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Study On The Prevalence Of Gastrointestinal Symptoms in Young Children
With Pervasive Developmental Disorder

by
Jennifer Gelsinger

A Thesis

Submitted in partial fulfillment of the requirements of the
Masters of Arts Degree
of
The Graduate School
at
Rowan University
2001

Approved by _____
Date Approved 4/30/01

Abstract

Jennifer Gelsinger

Study on the Prevalence Of Gastrointestinal Symptoms in Young Children

With Pervasive Developmental Disorder

2001

Dr. J. Klanderman

Seminar in School Psychology

The objective of this study was to gather information on the prevalence of the occurrence of gastrointestinal problems in a selected group of young children with pervasive developmental disorder. The purpose of this study was to learn more about the eating, sleeping, and toileting habits of the selected group of children with PDD; and identify how these habits may or may not relate to the behavior exhibited by the children.

The sample for the study consisted of 50 children with pervasive developmental disorder, ages 2.5 to 12 years of age. All of the children had a post-diagnosis of PDD for at least six months. The participants were recruited from two organizations located in New Jersey. The researcher developed a 47-item questionnaire specifically for the study.

The design of the study was conducted to establish the prevalence of gastrointestinal symptoms, as reported by caregivers, in 50 children with PDD. It was hypothesized that a positive relationship would exist between parental report of the occurrence of gastrointestinal problems and the eating, sleeping, and toileting behaviors of their child.

Mini-Abstract

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The objective of this study was to gather information on the prevalence of the occurrence of gastrointestinal problems in a group of 50 children with pervasive developmental disorder. It was hypothesized that a positive relationship would exist between the occurrence of gastrointestinal problems and the behaviors exhibited by the children. The data collected presented intriguing information, but no statistical significance.

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Chapter 1

INTRODUCTION

Horvath, Papadimitriou, Rabszryn, Drachenberg, and Tildon (1999) have conducted studies to investigate the possibility that there exists a large population of children with Pervasive Developmental Disorders, who suffer with painful gastrointestinal problems. Pervasive Developmental Disorders are characterized by severe and pervasive impairment in several areas of development. The disorders included in this category are: Autistic Disorder, Rett's Disorder, Childhood Disintegrative Disorder, Asperger's Disorder, and Pervasive Developmental Disorder-Not Otherwise Specified. These disorders are usually evident within the first six years of life (DSM-IV, p.65). Findings from their research suggest the need for more comprehensive gastrointestinal evaluations for this population of children. These researchers found "a significant portion of autistic children had gastro esophageal reflux and reflux esophagitis" (Horvath, et al., 1999, p.562). Reflux is a flowing back, regurgitation. Esophagitis is an inflammation of the esophagus. The findings by Horvath et al. (1999) suggest that gastrointestinal abnormalities may contribute to some of the behavioral problems frequently described in children with pervasive developmental disorders. Professionals speculate that if the reflux is treated, the stereotypic behaviors of children with pervasive developmental disorders may decrease, which will increase their on-task, more normative behaviors (eye contact and better overall control). Stereotypic behaviors

are recognized as the following: an encompassing preoccupation with one or more stereotyped and restricted patterns of interest, that is abnormal either in intensity or focus; an apparently inflexible adherence to specific, non-functional routines or rituals; stereotyped and repetitive motor mannerisms (i.e. hand-flapping, body-rocking, dipping or swaying); a persistent preoccupation with parts of objects; or a fascination with movement (i.e. spinning wheels of toys). The child may insist on sameness and show resistance or distress over trivial changes (DSM-IV, p.67). There is a need for further research in this area.

There is much speculation about the causes of pervasive developmental disorders, as well as the many treatments that exist to assist these children and their families to live happy, healthy, and productive lives. Children with pervasive developmental disorders exhibit a bewildering array of behavioral deficits in attention, cognition, speech, language, and affective and social functioning, together with behavioral excesses ranging from noncompliance to explosive, aggressive and self-injurious behavior (National Association of School Psychologists, 1999, p. 559). PDD is a developmental disorder in which the symptoms can and do change over time. Bauer (1995) states that researchers now have “a biologically based understanding of autism as a developmental disability that has an underlying neurological basis” (p. 130). There are three general categories of behavioral impairment that are common to all individuals who have pervasive developmental disorders. These categories are defined in the Diagnostic and Statistical Manual of Mental Disorders-Fourth Edition; more commonly referred to as the DSM-IV. First, there is a qualitative impairment in social functioning, which is commonly referred

to as a “lack of empathy.” Symptoms noted in the DSM-IV, under the category of “social deficit”, include deficient nonverbal forms of social communication (e.g. facial expression, eye contact, pointing), poor peer relationships, inability to appreciate others’ emotions, and lack of reciprocity in social interaction (Bauer, 1995, p.134). Second, there is a qualitative impairment in the development of language and communication. A delay in the onset of expressive language is a common characteristic of autism. Bauer (1995) states that the language of an individual with pervasive developmental disorder (PDD) tends to be rote, repetitive, and lacking in communicative meaning (p. 134). Third, there is a restricted range of activities and interest. Individuals with PDD seem to have a ‘cognitive inflexibility’; they have a tendency to be ritualistic in their daily activities. Research has shown that individuals with PDD have difficulty with transition, and do best with a predictable schedule and routines (Bauer, 1995, p. 135). The National Association of School Psychology (1999) recognizes other characteristics that are often associated with PDD to be engagement in repetitive activities and stereotypical movements, resistance to environmental change, unusual response to sensory experiences (e.g. smell, taste, touch, or pain), hyperactivity, high levels of anxiety, change in mood, and poor concentration (p. 543). The DSM-IV uses the term Pervasive Developmental Disorder (PDD) to describe the entire autistic spectrum. The disorders that make up this spectrum are Autism, Rett’s Disorder, Childhood Disintegrative Disorder (CDD), Asperger’s Disorder, and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). Modifications have been made so that the criteria recognize that the

symptoms in each category can range in severity from mild to severe; it also accounts for variations in symptoms across different ages and developmental levels (Bauer, 1995).

PDD is recognized as having onset early in life, usually within the first three years. There are many biological and psychological aspects of PDD. Bauer (1995) states that epidemiological studies have shown that PDD is frequently accompanied by mental retardation and the incidence of seizure disorders is increased significantly. The term *epidemiological studies*, stems from the word, epidemiology. Epidemiology is a branch of medical science that deals with the incidence, distribution, and control of disease in a population. There is some statistical association with a wide variety of other medical conditions (p. 133). There is also a general consensus that genetic factors play a role in PDD, as there is a slightly higher incidence rate within families (National Association of School Psychology, 1999).

Pervasive Developmental Disorder (PDD) is widely recognized as a lifelong neurodevelopmental disorder that affects the functioning of the brain. Bauer reports (1995) that several areas of the brain have been implicated in the condition of autism. Recent research suggests that some or all of the implicated areas may be likely because they are linked by complex neural connections. Some theories suggest a basic neurochemical defect, implicating the dopamine and serotonin systems most frequently (p. 133). Dopamine is a neurotransmitter in the brain. It is also an intermediate in the biosynthesis of epinephrine; which is a hormone that is the principal blood pressure raising hormone secreted by the adrenal medulla. Serotonin is a phenolic amine

neurotransmitter that is a powerful vasoconstrictor; it is found especially in the brain, blood serum, and gastric mucous membrane of mammals.

There are several differences of opinion among professionals when it comes to looking at the psychological aspects of PDD. Some professionals believe the “lack of empathy” in PDD is due primarily to cognition. Bauer (1995) reports that there is a cognitive hypothesis that suggests that children with pervasive developmental disorder lack a ‘theory of mind,’ meaning that they have an impaired cognitive ability to think about thoughts or to imagine another individual’s state of mind (p. 133).

The long-term prognosis of PDD is recognized as being relatively poor, but outcome varies from case to case. It is unlikely that any one cure will be found for PDD, given the various subtypes of this disorder and the existence of many underlying types of defects. However, PDD can be effectively managed using a combination of behavioral, educational, and biological intervention programs (National Association of School Psychology, 1999, p. 560). Bauer states that a management model is the most appropriate type of approach for the condition of PDD. This model should emphasize “support to the child and family, treatment of problematic symptoms and complications when possible, and intensive, continuous efforts to improve the overall functional status of the child” (1995, p. 172). Although there are many specialized programs available, an effective behavior management program that can be implemented in both, the home setting and the educational environment, may be the best treatment option. The general goal of any behavioral management program is to utilize reinforcement in a way that promotes desirable behaviors and reduces the occurrence of undesirable behaviors.

There are many other therapies and treatments that are available for children with pervasive developmental disorder. Treatments having little or no empirical support are facilitated communication, auditory integration training, sensory integration therapy, and changes in diet to cure 'allergy induced autism.' Although, there is a great deal of information available on these treatment options, and most of them are strongly endorsed by parents of children with PDD and professionals, there are no research studies to support a basis for their use in the treatment of PDD. A lack of empirical demonstration of efficacy does not necessarily mean a particular treatment is ineffective; but the ineffective treatments can be harmful if they replace effective treatments that might have been used. The uncertainty in both cause and treatment of PDD increases the need to explore all possibilities that may contribute knowledge to the study of PDD.

PURPOSE

This thesis will survey a selected group of children with pervasive developmental disorder. The researcher will distribute questionnaires to parents or guardians within two selected programs in New Jersey (see Appendix A). The researcher hopes to find evidence that there is a population of children with PDD who suffer with gastrointestinal problems. Gastrointestinal symptoms are symptoms of, relating to, or affecting both the stomach and intestine. The researcher's ultimate goal is to gather evidence that supports the need for further, in-depth studies to occur in this area of gastrointestinal medicine and PDD.

The objective of this research is to gather information on the prevalence of the occurrence of gastrointestinal problems in children with PDD. The purpose of this study is to learn more about the eating, sleeping, and toileting habits of a selected group of children with PDD; and how these habits may or may not relate to the behavior of these children.

This basic research intends to add more information to the existing body of knowledge in the area of pervasive developmental disorder and gastrointestinal medicine. The design of the study is developed to survey a selected population of children with PDD. The incidence of gastrointestinal problems in these children will be assessed by the design of the study.

HYPOTHESIS

It is hypothesized by the researcher, that a positive relationship exists between the occurrences of gastrointestinal problems in young children with PDD and their behavior. The researcher intends to investigate the following questions by conducting this study:

- What is the prevalence of gastrointestinal problems in young children with pervasive developmental disorder?
- Are the eating, sleeping, and toileting habits of this selected group of children with PDD indicative of the existence of a gastrointestinal condition?
- Does the data from this survey support the existing body of knowledge on the issue of gastrointestinal problems in young children with PDD?
- Does the data from this survey support the need for further research in the area of treatment for gastrointestinal problems in young children with PDD?
- Does a connection seem to be indicated to exist between the behavior of a child with PDD and the existence of a painful gastrointestinal condition in that child?

THEORY

In 1975 a woman named Ruth Sullivan, the mother of a boy with autism, speculated that there might be a biochemical error common to autism and a few other medical conditions. She was the Director of the Information and Referral Service of the National Society for Autistic Children at the time, and felt compelled to report her

“hunches” on a possible connection between autism, rheumatoid arthritis, celiac disease, and depression. Rheumatoid arthritis is usually a chronic disease that is of unknown cause and is characterized especially by pain, stiffness, swelling, inflammation, and sometimes destruction of the joints. Celiac disease is a chronic nutritional disorder, especially in young children, that is characterized by defective digestion and utilization of fats, and often by abdominal distention, diarrhea, and fatty stools. Her only purpose at the time, was to report the patterns she had seen with the families she had worked with, with the hope that this information might stimulate a serious investigation in the medical community (Sullivan, 1975). This article is significant because it did not stimulate an investigation; it is only within the past ten years that medical professionals have begun to research a possible connection between autism (now commonly referred to as pervasive developmental disorder or PDD) and gastrointestinal conditions.

Today, there are several theories that propose a cause, and some that propose effective treatment for PDD. The researcher will only cover some of these theories, for the purpose of this thesis. Special diets and nutritional intervention, (Adams and Conn, 1997) secretin, (Horvath et al., 1998) and the use of famotidine, which is the main ingredient in Pepcid, (Pedersen, Liu, and Reichelt, 1999) are a few of the things proposed to be useful for the treatment of children with PDD. Secretin is an intestinal proteinaceous hormone, capable of stimulating secretion by the pancreas and liver. Pepcid is presently a popular acid reducer that contains 10-mg. of Famotidine, and is sold over-the-counter and distributed by Johnson & Johnson and Merck. The mumps, measles, and rubella vaccination has recently been implicated in the cause of PDD

(Wakefield, 1998). Another growing body of research now suggests that the core of all PDD is a syndrome known as 'mindblindness' (Cowley, 2000). Recent research suggests that unrecognized gastrointestinal disorders, especially reflux esophagitis, may contribute to the behavioral problems of children with PDD (Horvath et al., 1999). Lastly, a difference in the brain chemistry of children with PDD has implicated abnormal brain development during gestation as a possible link to pervasive developmental disorder.

ASSUMPTIONS

For this study, the researcher assumes that the children selected for the study have been properly diagnosed by medical professionals, and are being treated properly for any condition that has been identified to exist within their minds or bodies.

The researcher also assumes that the adult who actually fills out the questionnaire is the person that they identify themselves to be; for example, the parent, grandparent, or guardian. The researcher then assumes that this adult took their time in completing the questionnaire, listed information in an accurate fashion, and read each question with a complete understanding of what was being asked in that particular question. The researcher also assumes that the child lives in the same household as the adult completing the questionnaire. Finally, the researcher assumes that the questions asked in the survey are phrased in a way and placed in an order, that when answered in an accurate and honest fashion, will lead to an indication of a relationship between the existence of a

gastrointestinal condition in a child that is reflected by their eating, sleeping, and toileting behaviors.

LIMITATIONS

The body of knowledge that exists for PDD is so vast and diverse that it is difficult to say, with any certainty, that a particular treatment will benefit any group of children with PDD. Much of the research done in this area of medicine has been inconclusive in their findings. Causes and treatments for PDD are often found to be in controversy among professionals, educators, and families of children with PDD.

OVERVIEW

In chapter 2, the researcher will review the extensive literature that is significant to the topic of this thesis. The substance of the ‘Theory’ section is looked at in some depth in this chapter. In chapter 3, the researcher will present the design of the study to the reader. Finally, in chapter 4, the researcher will analyze and discuss the findings of the study.

Chapter 2

Literature Review

Introduction

In this chapter, the researcher reviews the array of literature that has contributed pertinent information to the area of autism and gastrointestinal conditions. The beginning of the chapter presents the reader with an overview of the history of research conducted in this area, and looks at the period of time in which this research has taken place. The body of chapter 2 covers several categories of research that contribute significant information to the topic of the researcher's thesis.

The literature that the researcher reviews for this thesis can be classified into two broad categories, causes and treatments of autism. Since the researcher chose to look at the literature in-depth, the researcher establishes several sections, so that the reader may develop a clear understanding of the theories that contribute significantly to this thesis. The following areas are covered in some depth in this chapter: *general information on toileting, feeding, and sleeping behaviors of children with autism; neurological connections; gastrointestinal connections; the measles, mumps, and rubella vaccine; secretin treatment; biological and biochemical interventions (nutrition and its relationship to autism); the immune system; and psychopharmacology in autism*. The researcher begins with the literature that is most general to the purpose of this thesis, and proceeds to focus on those specific areas of research that contribute the most significant information to the thesis. Finally, chapter 2 concludes with a summary in which the

researcher discusses the implications of all the previous work in the area, and provides the reader with a direction for chapter 3.

Historical Overview

All of the major work done in the area of pervasive developmental disorder (PDD) and gastrointestinal conditions has occurred within the last five years. There has been some work done in the general area of identifying a possible cause and probable treatments for PDD, in relation to the topic of this thesis, done in the last ten years.

One article, written by Ruth Sullivan in 1975, has been identified as establishing the root of research for this thesis. At the time Ms. Sullivan wrote the article, she was the Director of the Information and Referral Service of the National Society for Autistic Children in West Virginia. She stated her purpose for writing the article as, “hope that the information reported here and the hunches I have formulated will suggest researchable questions.” Ms. Sullivan was, herself, the parent of an autistic child, as well as an observer, for almost a decade, of other parents and of children with autism. In her report, she proposed a possible connection between autism, rheumatoid arthritis (RA), celiac disease, and depression (1975, p. 177).

The researcher’s main reason for identifying this article, for the purpose of this thesis, is due to the connection Ms. Sullivan makes between gastrointestinal problems and autism. (Today, autism is commonly called Pervasive Developmental Disorder). One significant piece in her article brings attention to the use of a gluten-free diet for patients

with both, rheumatoid arthritis and celiac disease, dating back to 1964 (p. 179). Later in the chapter, the researcher has reviewed recent information that proposes a gluten-free diet for children with PDD. Ms. Sullivan also cites Dr. Curtis Dohan from the University College Hospital in London, as stating, in 1968, “recurrent gastrointestinal upsets are a constant feature of autistic children” (p. 180).

This article provides evidence that a connection between PDD and gastrointestinal symptoms is not a new theory. Although it is only within the past five years that professionals have conducted studies to examine this relationship more closely. Ms. Sullivan also implicates the immune system, blood types, serotonin, and a genetic component as playing a possible role in autism, in the article. All of these areas have been implicated in recent studies, and significant literary pieces will be reviewed by the researcher in some of the following sections of this chapter.

General information on feeding, toileting, and sleeping behaviors of children with autism

In this section of the chapter, the researcher reviews some of the general information related to the daily management of a child with PDD. Three of those aspects that are significant to this thesis are feeding, toileting skills, and sleeping and bedtime behavior.

O’Moore (1978) interviewed twenty-five Irish mothers of children with autism to illuminate the problems which arise in the daily care of a child with autism (p.33). Her survey of these families concluded that, “autistic children needed extra maternal attention

in feeding, toilet-training, dressing, and keeping them amused and getting them to go to sleep” (O’Moore, p. 37). 60% of the children surveyed in the study were found to have some difficulty at feeding time, and 13 of the children had a “food fad” of some sort. For example, one child would not eat meat, another would not eat bread, and a third child would not eat food if someone else touched the food (p. 36).

Toilet training was reported to produce the greatest difficulties, by the mothers. Of the twenty-five children surveyed in the study, seventeen children used the toilet, but only thirteen of these children could manage independently. O’Moore found that many of the children required a great deal of help in this area of functioning. The mothers reported constipation (due to anxiety), bed-wetting, and selectivity in toilet habits (in two cases) as some of the common areas of concern (p.36).

O’Moore found that 88% of the children in the study presented no sleeping problems once asleep. Parents reported that getting the children to go to sleep was the area of most difficulty for them (p. 37). In this study, O’Moore reports that “the children’s wakefulness was attributed to them not being tired enough at bedtime” (p. 38).

In 1992, Dalrymple and Ruble surveyed 100 parents of individuals with PDD, to identify common toileting problems. “The most common problems reported were urinating in places other than the toilet, constipation, stuffing-up toilets, continually flushing, or smearing feces” (p.265). Dalrymple and Ruble found that verbal and cognitive levels related significantly to age of starting and age of accomplishing bowel training, as well as to age of ceasing to wear diapers (p. 270-271). At the time of the study, 39% of the sample had current toileting problems associated with fears and

constipation (p. 272). Dalrymple and Ruble concluded that there was a significant relationship between verbal and cognitive levels and current toileting problems (p. 272).

An article in the Australian's Nurses' Journal (1972) identifies the inability to cope with any change in routine, as a "very real problem for most autistic children" (Scannell, p.25). It gives the example of a child, who had been admitted to an institution at the age of six, almost dying of starvation because "he fretted so badly for the familiar surroundings of his home" (p. 25). This article also identifies children with autism as "faddy eaters." Dalrymple and Ruble (1992) also reported a change in routine or bathroom, as reasons for regressions and problems in the toileting behaviors of a child with PDD, in their study (p. 273).

Stroh, Robinson, and Stroh (1986) report that feeding problems are almost always present as one of the specific problems and behaviors of children with pervasive developmental disorder (PDD). "Some children have ravenous appetites, others eat very little; but almost all have odd eating habits and preferences" (p.4). Hagopian, Farrell, and Amari (1996) conducted a study to report the treatment of a 12 year-old boy with PDD, for life-threatening gastrointestinal conditions. One team of researchers conducted a study to compare the breastfeeding rates of children with PDD with a control group. The researchers found that children with PDD were not less responsive to breastfeeding than other children with developmental delays. Actually, the data suggests that decreased parental nurturance may be an effect of having a child with PDD, rather than a cause (Burd, Fisher, Kerbeshian, Vesely, Durgin, and Reep; 1988, p. 250).

Archer and Szatmari (1991) conducted a study to evaluate the eating and mealtime problems of 33 young, high-functioning children with PDD. The results of the study showed that 42% of the children had a significant eating/mealtime problem. Archer and Szatmari found that “the presence of eating/mealtime problems was positively correlated with parent reports of greater severity of autistic behaviors and greater perceived stress in the parenting role, but not with the child’s intelligence level” (p. 3). This finding that IQ level and an eating problem were not positively correlated, suggests that there are other factors, for children with PDD, that may be more important in the development of an eating/mealtime problem (1991, p. 11).

Diagnosing a feeding disorder for a child with PDD may be very difficult. It is important that a thorough medical evaluation occur, so that organic and/or psychological etiology may be established; and the level of medical intervention may be determined by the professional (Steiner, 1997, p.192).

Nutrition and Its Relationship to Autism (Biological and Biochemical Interventions)

Secrist-Mertz, Brotherson, Oakland, and Litchfield (1997) reported that nutrition and feeding problems are often associated with almost all types of disabilities (p. 153). To successfully address the nutrition problems of children with disabilities, Secrist-Mertz et al. suggest the use of an integrated model. This model should incorporate the physical

and nutritional characteristics of the child, the interactions between the child and parent, and the child's behaviors associated with feeding (p. 152).

Literature describing PDD often includes information pertaining to abnormal feeding behaviors. Clark, Rhoden, and Turner describe the case of an 8 year-old boy with PDD who only consumed french fries and water for several years (1993, p. 284). The boy had vitamin A and D deficiencies due to his self-imposed diet; but once he received treatment with appropriate nutritional supplementation, all biochemical and physical abnormalities reversed (p. 284). Some researchers have developed behavior modification programs that are aimed at correcting feeding abnormalities in children with PDD. These programs are based on the assumption that the behavioral manifestations of PDD result in improper diets. For example, a 15 year-old boy with PDD was treated for persistent rummative vomiting using a program that included a combination of dietary, nutritional, and behavioral procedures (Medeiros, Jasinowski, Smith and Cameron, 1994).

Raiten and Massaro (1986) developed a questionnaire to distribute to a sample of 40 parents of children with PDD, to obtain data on nutrition and health issues, attitudes and beliefs about nutrition, and nutrition knowledge. It was found that the parents/caregivers of the children reported a positive belief in the relationship between diet and behavior, and a more positive attitude about the importance of nutrition (p.141).

This belief that the diet of a child with PDD impacts upon their behavior is popular among many parents and professionals. This becomes evident when an individual goes to the website of the Great Plains Laboratory. The site promotes the belief that the behavioral characteristics of PDD can be lessened with dietary intervention.

Some popular interventions include the gluten and casein free diet, vitamin therapy, and allergy elimination techniques.

The U.K. Based charity, AiA, states that it is “dedicated to identifying the underlying causes and biochemical effects of autism spectrum disorders” (Allergy induced Autism, 1997). This group promotes dietary intervention as a way to alleviate some of the physical symptoms and behaviors of PDD. “Allergy-induced autism,” is reported to occur when children ingest certain foods and/or chemicals. This website reports that the autism spectrum continuum may consist of a series of sub-groups, each with a slightly different bio-chemical profile (1997).

AiA reports that the Royal Free Hospital in London has identified many children with PDD as suffering with “autistic enterocolitis,” a serious gastrointestinal condition that causes a great deal of pain. Professor Karl Reichelt and Paul Shattock are reported to have confirmed the presence of excess opioids in the urine of children and adults with PDD. Opioid peptides have been shown to act in the brain to inhibit gastric acid and pepsin secretion. This is commonly referred to as the “opioid excess theory.” These two gentlemen propose that “autistic disorders result from the incomplete breakdown and excessive absorption of gut-derived peptides from foods, including barley, rye, oats, and casein from milk and dairy products” (related comments in Lancet, 1998). Removal of gluten and casein from the diet is reported to have a beneficial effect upon the individuals with excess opioids in their urine. Dr. Alan Friedman, from Johnson and Johnson Ortho Clinical Diagnostics, reports, “there is now industrial confirmation of the existence of abnormal dietary peptides (partial breakdown products of protein) in the urine of

autistics, in addition to other neurotoxic substances that may also diminish after the gluten and casein free diet is implemented (DAN conference, 1998). Dr. Rosemary Waring is also reported to have proved that there is a fault in the natural detoxification systems of some children with PDD, and because of this there are certain foods and used neurotransmitters that are not efficiently processed by the body of that child. There is no empirical data to validate the proposed findings and suggested treatments on this website.

Adams and Conn (1997) discuss the relationship between PDD and Candidiasis, food sensitivities/allergies, and megavitamin intervention in their report. Candidiasis is the over growth of intestinal yeast, which is reported to result in symptoms often associated with PDD. These symptoms are the absence or abnormal use of language, social isolation, and decreased eye contact (p. 53). Adams and Conn also give testimony that “food allergies and sensitivities have been shown to produce a variety of neurological signs associated with autism” (1997, p. 53). Studies have shown that the use of megavitamin therapy in PDD has demonstrated a decrease in stereotypic behaviors: such as, tantrums, echolalia, and self-injurious behavior (Adams and Conn, p. 53). The researchers included two case studies in their report, to illustrate the relationship between PDD and nutrition. Although, Adams and Conn describe evidence of positive changes after the implementation of diet/vitamin therapy in both case studies, the need for further, well-controlled research is concluded in the report (p.57). In order to establish a relationship between changes in social, communicative, and cognitive abilities, with diet/vitamin therapy, empirical validation must concur in future investigations (p.57).

Neurological Connections to Autism

Recently, a syndrome known as “mindblindness” has been implicated in the cause of PDD (Cowley, 2000). This theory supports the belief that the brain is wired differently in individuals with PDD. There is blindness to contextual clues, and that affects the individual’s social development. Neural-imaging studies are showing differences in how autistic and non-autistic brains respond to social cues (Cowley, p.51). Cowley also reports that “autopsies of autistic people have found that cells in the “limbic” regions that mediate social behavior are often small and densely packed, suggesting their early development was interrupted” (p.51). Limbic regions are regions of, relating to, or being the limbic system of the brain. The Limbic system is a group of subcortical structures, such as the hypothalamus, the hippocampus, and the amygdala, of the brain that are concerned especially with emotion and motivation.

Research conducted by Raymond, Bauman, and Kemper (1996) implicate the hippocampus in PDD. The hippocampus is a curved, elongated ridge that is an important part of the limbic system; it extends over the floor of the descending horn of each lateral ventricle of the brain, and consists of gray matter covered on the ventricular surface with white matter. Their work supports the need for further study of neural structure in additional regions of the limbic system as well as other areas of the hippocampal complex in autism (1996, p.119). “The relationship between cognitive level and behaviors is

complicated by the fact that cognitive factors influence different behaviors in different ways across various domains”(Prior et al., 1998, p.894). It is suggested by researchers that there is a basic dysfunction in the neurological systems that promote mentalising functions (Prior et al., p.894). Prior et al. discovered that “a child’s level of cognitive and language competence has a general influence on all domains of functioning, including mentalising ability” (p.900).). Mentalising ability is an ability of, or relating to the mind; of or relating to the total emotional and intellectual response of an individual to external reality.

Psychopharmacology in Autism

Research conducted by Tsai strongly suggests that neurochemical factors play a major role in PDD. Neurochemical factors are factors relating to the chemical processes and phenomena related to the nervous system. These findings also provide a rationale for psychopharmacotherapy in individuals with autism (1999, p.651).

Psychopharmacotherapy is therapy relating to the study of the effect of drugs on the mind and behavior. “Recent studies discovered that about one-third of persons with autism were taking some psychotropic drug or vitamin for autism or associated behavior or psychiatric problems “(Tsai, p. 652).

Medications are frequently used as one method of treatment in pervasive developmental disorders. Tranquilizers and antidepressants have been used to ease the anxiety and compulsiveness in individuals with PDD. Ritalin has been used to aid

children with PDD focus their attention more easily (Cowley, 2000, p.53). Haloperidol has been reported to improve coordination, self-core, affect, and exploratory behavior; reduce hyperactivity, withdrawal, fidgeting, and temper tantrums (Tsai p.654). Research has found in some cases, that dopamine antagonists, such as stimulants, have been noted to cause worsening of pre-existing stereotypes, aggression, and hyperactivity. This suggests a role of the dopamine system in PDD symptomatology (Tsai, p.654).

A report in 1997, by Linday, suggests that famotidine, more commonly known as Pepcid, may be useful in treating children with PDD. Pepcid is a popular acid reducer that contains 10-mg. of famotidine, and is used for the treatment of peptic ulcer disease, gastroesophageal reflux, and a few other medical conditions. It is sold over-the-counter and distributed by Johnson & Johnson and Merck. Linday's hypothesis that famotidine may be useful in treating children with PDD is based on the connection he makes between pervasive developmental disorder and schizophrenia (p. 381). However, Linday states, "given the severity of autism and the need for new treatments for this disorder, evaluation of the safety and efficacy of famotidine in the treatment of children with autism is warranted"(p.385).

Serotonin has been implicated in the condition of PDD by Tsai (1999) and also in a report written by Pedersen, Liu, and Reichelt (1999). A large group of researchers have stated that, " the results of recent clinical trials indicate that serotonergic drugs can lessen the severity of symptoms associated with autism and related conditions" (Sandler, Sutton, DeWeese, Girardi, Sheppard, and Bodfish, 1999). The belief that serotonin plays a role in the condition of PDD stems from a theory of "abnormal intestinal permeability,

according to which excessive absorption of peptides, which are molecules formed of a small number of amino acids-below 100, derived from the gut may affect central serotonergic, opioid, and perhaps other neurotransmitter systems” (Sandler, et al., 1999, p. 1801).

Autism and the Measles, Mumps, and Rubella Vaccine

In July of 2000, Newsweek published their magazine with the cover entitled, “Understanding Autism.” One of the article inside focused on the recent controversy of the measles, mumps, and rubella vaccine as being linked to the cause of PDD. The article cited a study conducted by Dr. Andrew Wakefield of the Royal Free Hospital in London. The Lancet, a prestigious, peer reviewed journal, first reported Dr. Wakefield’s results in 1998. Dr. Wakefield studied a group of twelve children with PDD who also had several and persistent gastrointestinal problems, including abdominal pain, diarrhea, bloating, and some degree of food intolerance (Lancet, 1998). Dr. Wakefield et al. reported that parents and/or physicians of eight of the children in the study, linked the onset of behavioral problems with the administration of the MMR vaccination. In the discussion section of the report, Dr. Wakefield et al., states that the study, along with other studies which have found intestinal dysfunctional in children with autism-spectrum disorders, suggests that there is a real connection between inflamed or dysfunctional

intestine and behavioral changes in children diagnosed with PDD, and that “a unique disease process is reflected “in the results of the study (1998, P. 641).

This study caused great upset in the medical community, which is apparent in the literature that comes after the publication of Dr. Wakefield’s study. Some of the literature recognizes Dr. Wakefield’s work in the area of Inflammatory Bowel Disease and Crohn’s disease. The Lancet (1995) published a study conducted by Thompson, Montgomery, Pounder, and Wakefield that suggested that there is an association between measles vaccination and inflammatory bowel disease, although it is not a causal relationship (1995, p. 1072). One person comments, “there is no report of detection of vaccine viruses in the bowel, brain, or any other tissue of the patients in Wakefield’s series” (related comments in Lancet, 1998); another person expresses other reasons for doubt about the association suggested between MMR vaccination and Inflammatory Bowel Disease, stating, “behavioral changes proceeded bowel symptoms in almost all their reported cases.”

Many other professionals find fault with Wakefield’s study on PDD and the MMR vaccine, due to a lack of control in patient selection and lack of explicit detail in the administration of the MMR vaccine in several of the twelve cases (comment in Lancet, 1998, p. 905). Fombonne states his criticism, while implicating both of Wakefield’s et al.’s studies focusing on the MMR vaccine. He asks, “if measles viruses were implicated in both autism and inflammatory bowel diseases, then, surely there should be an association between autism and inflammatory bowel disease” (1999, p.349).

Despite the criticism that Dr. Wakefield et al. received for their study, parents are concerned about the safety of using the vaccine on their children. Rick Rollens testified before the House Committee on Government Reform, on behalf of his son, Russell. He believes that Russell has vaccine-induced autism (Washington Times, 1999). All empirical data denies any link between MMR vaccination and bowel disease or pervasive developmental disorder; the researcher has been unable to identify any new research that speaks to the contrary, up to the present time.

Although the study conducted by Dr. Wakefield et al. received much criticism, Dr. Wakefield stands firm on his suggestion that pediatric gastroenterologists investigate further in this area. Murch, Thomson, and Walker-Smith re-emphasize “the fact that there is a consistent pattern of gut inflammation in a high proportion of children with autistic spectrum,” in their comments. They propose that “understanding the link between the bowel and the brain in autism may allow new insights into this devastating illness” (Lancet, 1998, p. 908).

Secretin and Its Use in Autism

There have been many cases in which parents of children with PDD have reported chronic diarrhea and a variety of other gastrointestinal symptoms as being present in their child. “Secretin is a peptide hormone that stimulates pancreatic secretion” (Sandler et al.,

1999). Pancreatic secretions are produced in or related to the pancreas. The pancreas is responsible for secreting digestive enzymes, which pass to the intestine and function in the breakdown of proteins, fats, and carbohydrates. There was a three year-old boy with PDD who recently received an intravenous administration of secretin to address some gastrointestinal problems he was experiencing; within a week his parents noted drastic improvements in his behavior and language skills (Sandler et al., p. 1801). This case began a media frenzy that has many parents hoping secretin may represent a “cure” for PDD. At the DAN conference in 1998, PDD was boldly referred to as a gastrointestinal disorder. At the conference, the administration of secretin was reported to improve functioning in certain individuals with PDD, in addition to alleviating some gastrointestinal symptoms in these individuals. The gluten and casein free diet has been reported to be a very important part of the treatment with secretin infusions, by one doctor at the conference (1998).

Although, a study of 56 children with PDD conducted by Sandler et al. (1999) concluded that “a single dose of synthetic human secretin is not an effective treatment for autism or pervasive developmental disorder,” a literary piece in the *Journal of Child Neurology* (July, 2000) reports that “secretin so far has proved no better than a dummy injection,” some professionals are still convinced it warrants a closer look. The observations from a recent study of three children with PDD, conducted by Horvath, Stefanatos, Sokolski, Wachtel, Nabors, and Tildon (1998) did suggest an association between gastrointestinal and brain function in persons with autistic behavior. Horvath et al., report, “within five weeks of the secretin infusion, a significant amelioration of the

children's gastrointestinal symptoms was observed, as was a dramatic improvement in their behavior, manifested by improved eye contact, alertness, and expansion of expressive language" (1998, p.9). Evaluations after the secretin administration were based on the reports of therapists and teachers and interviews with parents, all of which knew nothing about the treatment.

This study gives strong evidence of a gut-brain relation in pervasive developmental disorders, because of the effect that secretin has on the central nervous system, and because of the general purpose for which it is used, "to reset or normalize gastrointestinal function." Horvath et al. do state that "the improvement in behavior and developmental functioning of the three children after the secretin administration may be either a direct or indirect effect of secretin;" they do propose that further research is needed in the area of gastrointestinal symptoms and behavioral/developmental functioning in children with PDD. This particle article gives strong support to the researcher's purpose for conducting this thesis.

The Immune System and Autism

"Recent studies suggest that a sub-group of children with autism have immune system deficiencies" (Mason-Brothers, Ritvo, Freeman, Jorde, Pingree, McMahan, Jensen, Petersen, and Mo, 1993, p.79). Dr. Friedman presented information at the DAN conference (1998) that implicated the enzyme CD26, which is used to activate T-cells, in immune function. He stated that he believes that this enzyme is either blocked or

deficient in individuals with PDD (Autism Network for Dietary Intervention). Dr. Wakefield stated in an interview that there is good evidence that children with PDD have compromised immune systems (Autism Network for Dietary Intervention).

Plioplys (1998) published results that “indicate that there is a subset of autistic children whose neurologic disability is due to autoimmune factors.” He reported that 10% of children with autism responded to treatment with intravenous immunoglobulin. He further stated “autistic children with unrecognized epileptiform discharges on sleep EEG tracings can have very significant clinical improvements with the use of anticonvulsants.”

Dr. Sudhir Gupta responded in a letter to the editor of *The Journal of Child Neurology* (1999), to the study conducted by Plioplys by stating, “based upon the extreme heterogeneity of the study of subjects and the unconventional treatment protocol used, the conclusions by Plioplys with regard to the efficacy of immunoglobulin in autism are premature and unwarranted” (p.203). Plioplys’ findings were in direct contrast to those findings published by Gupta et al (1996), “who demonstrated improvement in a majority of children with autism following treatment with immunoglobulin.” Gupta concludes her correspondence to the editor of *The Journal of Child Neurology* (1999), by stating that the results of a study being conducted, “to establish the efficacy of immunoglobulin, or lack of it, in autism (regardless of immune status), should be available to the public within one year.”

Gastrointestinal Abnormalities and Autism

Horvath, Papadimitriou, Rabszty, Drachenberg, and Tildon present the most compelling findings to encourage further investigation in this area. These researchers presented evidence that supported “a higher than expected prevalence of gastrointestinal disease among children with autism” (Accardo and Bostwick, 1999, p.533). It is clearly stated in one of their articles that pervasive developmental disorder is not ready to be classified as a gastrointestinal condition, but that the association warrants further research (Accardo and Bostwick, 1999, p. 534). Horvath et al. credit Dr. Wakefield’s research as “the first effort to evaluate the gastrointestinal tract in children with autism” (Horvath, Papadimitriou, Rabszty, Drachenberg, and Tildon, 1999, p.559). These researchers described, “sudden unexplained irritability or aggressive behavior, nighttime awakening, and pushing on the abdomen,” as behavioral problems that are typically associated with PDD (p.559). A study was conducted by Horvath et al. to evaluate the possible relationship between the behavioral symptoms of a child with PDD and any gastrointestinal symptoms that the child may have been suffering from, as reported by the child’s parent. There were 36 children surveyed in the study, and all of the children suffered from one or more of the following symptoms, including abdominal pain, chronic diarrhea, gaseousness/bloating, nighttime awakening, and unexplained irritability (p.560). The results of the study indicated, “unrecognized gastrointestinal abnormalities may contribute to some of the behavioral problems frequently described in non-verbal

children with autism” (p. 563). “The most frequent finding was the presence of reflux esophagitis in 25 of the 36 children” (p.561).

The study by Horvath et al. “demonstrates consistent physiologic abnormalities in autism that are not known to occur in any other specific gastrointestinal disorder” (p.534); these findings suggest that comprehensive gastrointestinal evaluations should be conducted for low-functioning children with PDD (p. 560). The study conducted by Horvath et al. encourages further research to determine “ a possible association between the brain and gastrointestinal dysfunctions in children with autism” (1999).

Summary

All of the articles reviewed in this chapter contribute significant background information and theory to the researcher’s thesis. The design of the thesis incorporates theory from the literature mentioned in this chapter; some research is weighted more heavily than others. This literature review is extensive and thorough, going back to 1975 and ending within the last five years, when the most pertinent information has been gathered in studies conducted by professionals.

Chapter 3

Sample

The samples for this study were 50 children with pervasive developmental disorder (2.5 to 12 years of age). All children had a post-diagnosis of autism for at least six months. The sample was comprised of 9 females, 38 males, and 3 children whose gender was not identified by the parent. 11 of the surveys completed were representative of children enrolled in the pre-school in Southern New Jersey, while 39 of the surveys completed were representative of members belonging to the other organization, and living in Middlesex and Burlington counties of New Jersey.

The participants were recruited from two organizations located in New Jersey. One organization was a non-profit agency that provides outreach services throughout the state of New Jersey to children with autism and their families. Information about the services provided by this organization can be obtained by calling the organization's Autism Information and Referral Line. The other location was a pre-school located in Southern New Jersey in a suburban setting. It is a day school that provides educational services to children with any of the disorders included in the category of Pervasive Developmental Disorders and multiple disabilities. The researcher contacted the Director of Children and Family Services at both locations, by phone. The purpose of the study was explained to both individuals, and the researcher secured interest in the project, from both organizations.

Measure

The researcher developed a 47-item questionnaire specifically for this study. An article written by Secrist-Mertz, Brotherson, Oakland, and Litchfield (1997) was helpful in the researcher's initial thinking of the assessment tool for this study. This tool was designed to be a comprehensive assessment of the child's behaviors, eating, and sleeping habits as they relate to the child's autistic condition. The individual completing the questionnaire was asked to identify which diagnosis the child had been given in the category of Pervasive Developmental Disorders. All of the questions were derived from the extensive literature, in the area of gastrointestinal problems and autism, reviewed by the researcher in chapter 2 of this thesis. Originally, approximately 75 items were identified, but after careful review of the literature, approximately 25 questions were deleted, due to redundancies or insufficient support in the literature. The original survey also included a separate section for the father and a separate section for the mother to complete, in addition to the section to be completed on behalf of the child. Each of these sections asked questions that pertained to the health and habits of the parent. After careful deliberation, the faculty sponsor and researcher decided that this section should be removed because it diluted the scope of the study. All of the questions in the revised survey reflect some aspect of current interest in the suggested relationship between

autism and gastrointestinal problems. Two developmental pediatricians, both recognized nationally as feeding specialists, reviewed the questionnaire for accuracy and readability. The researcher also pilot-tested the survey on co-workers, for ease of understanding and readability.

The resulting survey consisted of 3 questions pertaining to pain resulting from stomach problems, 17 questions pertaining to feeding/eating habits and concerns, 7 questions pertaining to toileting habits, 4 questions pertaining to swallowing/vomiting behaviors, 8 questions pertaining to behaviors exhibited by the child, and 8 questions pertaining to medical concerns and conditions and treatments for the child. Some of the questions require the parent to circle a simple “yes” or “no” answer, other questions require a short written response, and still other questions require the parent(s) or guardian(s) to respond using a 5-point Likert Scale. Archer, Rosenbaum, and Streiner (1990), developed an eating inventory that was instrumental in the researcher’s development of this survey.

Design

This is a descriptive study conducted to establish the prevalence of gastrointestinal symptoms, as reported by caregivers, in 50 children with autism. A secondary goal is to investigate the relationship between gastrointestinal symptoms and eating habits in this population.

The design of the survey can be identified as a cross-sectional design because it involves the collection of data at one point in time from a random sample representing a given population at that time. The purpose of the design of the research is to provide answers to the research questions stated in Chapter 1.

Random selection was used in the design of this research. Two counties were selected for the sample. Trenton was established as the dividing line for the state of New Jersey, and Middlesex County was selected to represent North Jersey, while Burlington County was selected to represent South Jersey. The pre-school was located in Camden County, which also represented South Jersey. Only members of the organization providing outreach services, living in Middlesex and Burlington Counties, were sampled; non-members were excluded from the study.

Procedure

The researcher received approval from the Institutional Review Board of Rowan University (see Appendix B). The researcher then contacted the appropriate individuals in the two organizations targeted for data collection, and received approval to distribute the questionnaires and other related materials to the parent(s) or guardian(s) working with the organizations (see Appendix C).

The Director of the pre-school program required that she review the materials before giving approval for the researcher to distribute the questionnaires. Approval was granted for the researcher to distribute 36 surveys to parents of children in the program. Due to issues of confidentiality at the pre-school, the researcher prepared packets of materials to be distributed by the staff of the agency. All materials were prepared by the researcher and given to the coordinator of the program to distribute to teachers in each classroom. The teachers placed the packages in the children's backpacks to be taken home to their parents.

On January 30 of 2001, the researcher went back to the pre-school and dropped off 36 copies of a follow-up letter to the Director of the program, because up until that time only 9 surveys had been completed and returned to the faculty sponsor (see Appendix D). The researcher also prepared 15 additional packages so that parents could request another copy if they had misplaced the original package they had received in November. At this point in time revisions had been made to both, the materials and the process, in an attempt to reduce the cost of the project. The survey was shortened slightly (see Appendix A) and the cover letter was revised so that the instructions were placed on that same page (see Appendix E) and the parents were to send all completed materials back to the faculty sponsor in one envelope. So the packages that were dropped off at the pre-school in January were slightly different than the original materials. The letters were placed in the children's backpacks the following day.

The researcher assumed that all children were present on that day of school, that every teacher placed a letter in each child's backpack, and therefore all parents received

the follow-up letter. The researcher also assumed that parents either still had the original materials or would request an additional package from the classroom teacher if they did not have the original materials.

The researcher prepared a package containing a copy of the Institutional Review Board's approval from Rowan University and all survey materials intended for the parents, so that the Board members of the organization providing outreach services throughout the state of New Jersey could review the materials. The Director informed the researcher that the Board met on November 14, and approved the researcher's request to submit the survey to parents belonging to the organization. The researcher received approval to survey 2000 parents within the organization.

The researcher and faculty sponsor decided to survey 200 parents that were members of the organization. It was established with the Office Manager of the organization that 100 surveys would be sent to parent members living in Middlesex County and 100 surveys would be sent to parent members living in Burlington County. The researcher constructed packages containing a questionnaire, a cover letter explaining the purpose of the study to parent(s) or guardian(s), a consent form, and a self-addressed, stamped envelope. Parent(s) or guardian(s) were provided with the option to inquire about the study in more detail, and could send in their request, along with the consent form, and completed survey, to the professor overseeing the researcher's work. Instructions for completing the questionnaire were clearly stated in the cover letter and parent(s) or guardian(s) were provided with phone numbers, so that they could contact the researcher or faculty sponsor with any questions they might have about the study.

Participation in the study was voluntary, and this was clearly indicated in a cover letter addressed to the parent(s) or guardian(s) of the child.

On February 26 of 2001, the researcher dropped of 200 postage-ready packages with return address labels, at the organization's central office in Ewing, New Jersey. The Office Manager placed the labels on the packages the following day, ensuring confidentiality of all members living in those counties, and sent the surveys out within that week.

The faculty sponsor was designated to receive the surveys, and would separate the consent forms and any requests for further details from the questionnaires, again as a measure to ensure the confidentiality of the individuals that participated in the study. The questionnaires were given to the researcher for data collection and analysis.

Testable Hypothesis

The researcher intended to find evidence that supported the most recent literary findings, which identified a high percentage of children with autism as suffering with gastrointestinal problems. It is hypothesized by the researcher that a positive relationship exists between parental self-report of the occurrence of gastrointestinal

problems in young children with autism and parental self-report of their eating behavior. The researcher believed the data from this survey would support the existing body of literature on the issue of gastrointestinal problems in young children with autism; and would confirm the need for further research in this area.

Analysis

The researcher in this study analyzed the frequency of endorsement of particular items, and identified a correlation between subjects receiving professional care for gastrointestinal symptoms with eating, sleeping, and other behaviors. The researcher used SPSS version 10.0 to analyze the data collected in this study. A frequency distribution was conducted for certain items in the survey, to indicate the prevalence of gastrointestinal symptoms in the sample, and identify any evidence of reflux in the sample of the study. The researcher hypothesized that a pattern would be discovered among certain questions in the survey. Those questions would pertain to the eating, toileting, and sleeping behaviors exhibited by the child. Any emerging pattern would support a relationship between the parental self-report of the occurrence of gastrointestinal problems and the eating, sleeping, and toileting behaviors of that child.

Chapter 4

Data analysis

Introduction

In chapter one, the researcher hypothesized that a positive relationship would exist between the occurrence of gastrointestinal problems, in the sample of this study, and their behavior. The researcher also proposed to investigate the prevalence of gastrointestinal problems among the sample; in addition to investigating the eating, sleeping, and toileting habits of this selected group, to identify any indication of the existence of a gastrointestinal condition.

Results

The results of this study have been summarized in this section of the thesis. The data collected does not clearly support a positive relationship between the occurrence of gastrointestinal problems in the sample, and their behavior. Although there is some intriguing information presented, there is no clear statistical significance in this study.

In Table 4.1, the researcher presents the number of parents who reported that their child is currently seeking professional help for feeding problems. 12 children in the sample are receiving professional help for an identified feeding problem. Table 4.2 identifies the type of professional care being provided to those 12 children in the sample.

Table 4.1 Prevalence of professional help sought for feeding problems

Q46

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid 1.00	12	24.0	24.0	24.0
2.00	38	76.0	76.0	100.0
Total	50	100.0	100.0	

Table 4.2 Type of care being administered

Q46A

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid	38	76.0	76.0	76.0
a behavioral consultant through COSAC	1	2.0	2.0	78.0
a nutritionist-see COMMENTS on survey	1	2.0	2.0	80.0
a nutritionist, placed on gluten-dairy free diet for 4 months	1	2.0	2.0	82.0
a Pediatrician, a Dietician, and a GI specialist	1	2.0	2.0	84.0
ABA teacher, a feeding program	1	2.0	2.0	86.0
allergy doctor	1	2.0	2.0	88.0
Barbara Jordan, for 2 years to address feeding problems	1	2.0	2.0	90.0
currently seeing a GI doctor	1	2.0	2.0	92.0
endocrinologist and school therapist	1	2.0	2.0	94.0
in preschool, going to address these problems	1	2.0	2.0	96.0
recently evaluated at Children's Hospital in Phila.	1	2.0	2.0	98.0
saw Dr. Kerwin through school-see COMMENTS in survey	1	2.0	2.0	100.0
Total	50	100.0	100.0	

Graph 4.1 is a visual interpretation of the percentage of subjects who are being treated professionally for identified feeding problems. 1.00 represents the 12 children receiving professional help, and 2.00 represents the 38 children that are not receiving any form of professional help for a feeding problem.

In Table 4.3, 4.4, and 4.5, the researcher identifies the prevalence of gastrointestinal problems revealed in the sample of the study. Table 4.3 demonstrates the number of children in the sample that show evidence of experiencing abdominal pain. The results of question 18 show that 2% of parents identified their child as exhibiting gestures that indicate abdominal pain a few times a day, 2% of parents reported evidence of pain 2-6 times a week, 16% reported evidence of pain less than once a week, 46% reported no evidence of abdominal pain, and 24% reported, "I don't know," to the question. Table 4.4 portrays the number of parents that reported their child's stomach as appearing bloated or hard and round at times. 6% of parents identified their child's stomach as appearing bloated or hard and round most of the day, 2% of parents reported evidence of bloating 2-6 times a week, 26% of parents reported this occurring less than once a week, 24% of parents reported no indications of bloating or swelling, and 30% of parents responded, "I don't know," to question 19. Table 4.5 indicates the number of children that vomit frequently in the study. 16% of parents reported that their child vomits less than once a week, 32% of parents reported that their child does not vomit at all, and 16% of parents reported, "I don't know," to question 21. Many of the parents did not indicate any answer to this question and instead left it blank. The results demonstrated in these three tables are statistically non-significant.

Graph 4.1 Interpretation of professional help being administered

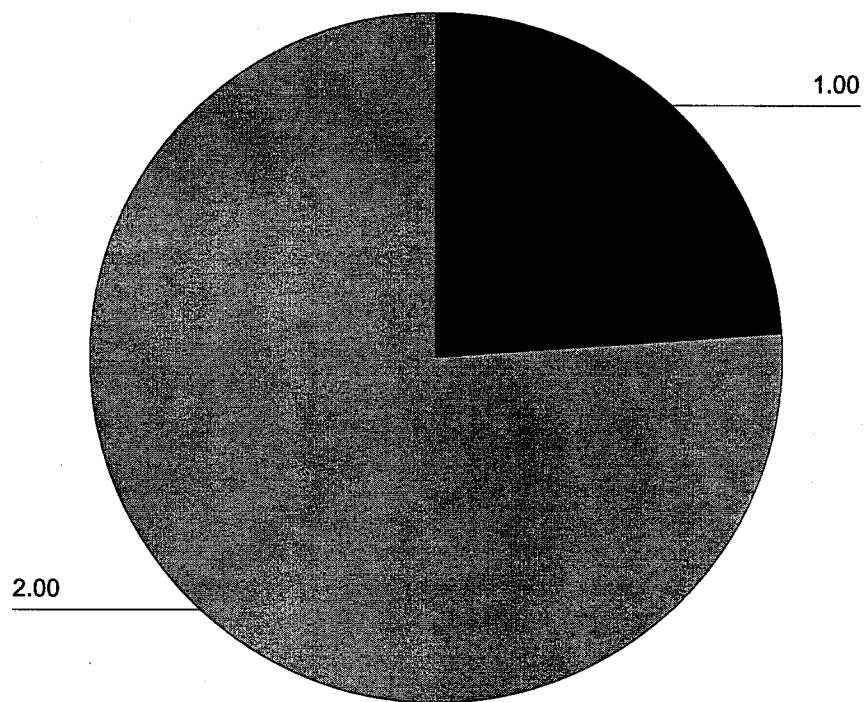


Table 4.3 Question 18 identifies evidence of abdominal pain**Q18**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	2.00	1	2.0	2.2	2.2
	3.00	1	2.0	2.2	4.4
	4.00	8	16.0	17.8	22.2
	5.00	23	46.0	51.1	73.3
	9.00	12	24.0	26.7	100.0
	Total	45	90.0	100.0	
Missing	System	5	10.0		
Total		50	100.0		

Table 4.4 Question 19 identifies evidence of bloating and swelling of stomach**Q19**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00	3	6.0	6.8	6.8
	3.00	1	2.0	2.3	9.1
	4.00	13	26.0	29.5	38.6
	5.00	12	24.0	27.3	65.9
	9.00	15	30.0	34.1	100.0
	Total	44	88.0	100.0	
Missing	System	6	12.0		
Total		50	100.0		

Table 4.5 Question 21 identifies frequency of vomiting**Q201**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	4.00	8	16.0	25.0	25.0
	5.00	16	32.0	50.0	75.0
	9.00	8	16.0	25.0	100.0
	Total	32	64.0	100.0	
Missing	System	18	36.0		
Total		50	100.0		

Although there is no generally recognized significance between the occurrence of gastrointestinal problems and the behavior of the subjects in the sample, there is one significant correlation found in this area of the study. The researcher identifies a correlation between the number of subjects seeking professional care for a feeding problem (Table 4.1), and the responses of parents to questions pertaining to eating, sleeping, and toileting habits of the sample, which may indicate the existence of a gastrointestinal condition in these subjects.

Table 4.6 demonstrates the significance between the number of parental reports of the existence of a feeding problem with their child, and the overall numbers of children in the study being given professional care for an identified feeding problem. 12 children in the study are receiving professional care for a feeding problem; 6 of those 12 children were identified by their parents as having a feeding problem, before professional care was sought out or received by the child. Analysis of the data identified $p \leq .008$, which is statistically significant.

Table 4.7 demonstrates a correlation between the number of children receiving professional care for an identified feeding problem and the number of children reported to wake up during the night. Analysis of Table 4.7 indicates the parents also reported 6 of the 12 children receiving professional care, as waking up during the night. Further analysis identified $p \leq .739$. There is no statistical significance found in this correlation, and the researcher speculates that this is because most parents reported that they were not aware of their child waking up in the night.

Table 4.6 Question 46 correlated with question 7

Crosstab

Count

		Q7		Total
		1.00	2.00	
Q46	1.00	6	6	12
	2.00	2	36	38
Total		8	42	50

Table 4.7 Question 46 correlated with question 33

Crosstab

Count

		Q303		Total
		1.00	2.00	
Q46	1.00	6	6	12
	2.00	20	16	36
Total		26	22	48

Table 4.8 Question 46 correlated with question 6

Crosstab

Count

		Q6		Total
		1.00	2.00	
Q46	1.00	5	5	10
	2.00	22	14	36
Total		27	19	46

A correlation is shown to exist between the number of children reported to have an unusual or unique eating habit and the number of children receiving professional care for a feeding problem. This correlation can also be seen in Table 4.8. 12 children in the study are receiving professional care for a feeding problem; of these 12 children, 5 were reported to have unusual or unique eating habits. Although a relationship appears to exist between these two variables, there is no statistical significance found in the analysis, because $p \leq .535$.

Discussion

Although there is no general significance found in this study, there is some interesting information that encourages further investigation into this area. A more concentrated and in-depth study into the relationship of gastrointestinal problems in young children with autism, and their eating, sleeping, and toileting behaviors may uncover some significant findings. The data collected does support the need for further research to be conducted in this area of medicine and science.

The study revealed no clear evidence of the occurrence of reflux in any of the children in the sample. The survey did not ask this question specifically, and none of the data collected in the sample indicates the presence of this condition in any of the children.

Summary

The results of the data analysis presented in this chapter tend to answer the basic research questions presented at the beginning of this paper. It appears that further research needs to be conducted in this area. Although there is no clearly identified positive relationship found to exist between the occurrence of gastrointestinal problems in the children in this study, and their behavior, there is adequate evidence to encourage further investigation of this relationship.

Chapter 5

Summary

The purpose of this thesis was to explore the possibility that a connection exists between Pervasive Developmental Disorder and painful gastrointestinal problems, specifically in young children. One group of researchers conducted a study and found, “a significant portion of autistic children had gastro esophageal reflux and reflux esophagitis” (Horvath, et al., 1999, p.562). These findings suggest that gastrointestinal abnormalities may contribute to some of the behavioral problems frequently described in children with pervasive developmental disorders. Professionals recently began speculating that if the gastrointestinal abnormalities are treated, than the stereotypic behaviors of children with pervasive developmental disorders may decrease, which would in turn; increase their on-task, more normative behaviors. In writing this thesis, the researcher hoped to add to the recent data in the scientific community, and show that there is a need for further, more in-depth studies to be conducted in the area of pervasive developmental disorders and gastrointestinal problems.

In chapter one, the researcher presented the theory behind the thesis. Several theories that propose a cause for pervasive developmental disorder were presented, in addition to a few theories that propose effective treatment for the category of disorders. In chapter two, the researcher selected those theories that contribute significantly to this thesis, and covered those areas in some depth, so that the reader developed a clear understanding of those theories. Those areas were: general information on toileting,

feeding, and sleeping behaviors of children with autism; neurological connections; gastrointestinal connections; the measles, mumps, and rubella vaccine; secretin treatment; biological and biochemical interventions (nutrition and its relationship to autism); the immune system; and psychopharmacology in autism. All of the articles reviewed contributed significant background information to the researcher's thesis, and the design of the thesis incorporated theory from the extensive literature covered in chapter two.

In chapter three of the thesis, the researcher presented the design of the study, which was a descriptive study conducted to establish the prevalence of gastrointestinal symptoms, as reported by caregivers, in 50 children with autism. A secondary goal was established for the purpose of investigating the relationship between gastrointestinal symptoms and eating habits in the selected population. The sample, measure, procedure, hypothesis, and analysis of the study were covered in detail in chapter three.

Conclusions

The researcher hypothesized that a positive relationship would exist between the occurrences of gastrointestinal problems in young children with pervasive developmental disorder and their behavior. This hypothesis was broken down into several, more specific research questions in chapter one. The data collected in the study does not clearly support the existence of a positive relationship between the occurrence of gastrointestinal problems in the sample, and their behavior; but there is some intriguing information presented in the data.

The first research question addresses the issue of prevalence of gastrointestinal problems in the sample of the study. Although this question could not be specifically answered by the data collected in the study, it is clear that 12 of the 50 children in the sample are seeking professional care for an identified feeding problem. The parents of these 12 children then went on to identify the type of care being sought, and gave a description of the professional administering the care to the child.

The second research question addressed particular habits of the child that might be indicative of a gastrointestinal condition. A clear relationship could not be identified by the data collected in the study.

The third research question addressed the literature covered in the thesis and the data collected in the study. Again, a clear distinction cannot be made from the data collected, but there is enough information in the 50 surveys to state that the data does support the existing body of knowledge on the topic of gastrointestinal problems in young children with pervasive developmental disorders.

The fourth research question addresses the need for further research based on the data collected in the study. The data does support a need for further research in the area of gastrointestinal problems in young children with PDD, because a group of professionals with financial and medical resources need to do more, in-depth studies in this area in order to collect the kind of detailed information needed to verify the existence of a relationship between the two variables.

The final research question addresses the indication of a connection between the behavior of the children in the sample and the existence of a gastrointestinal condition in those children. The data collected in the study does not propose any general significant

findings in this area, although Tables 4.6, 4.7, and 4.8 do present the reader with some interesting information.

Discussion

Although the researcher did not identify statistical significance in this study, the data collected did present some intriguing findings. The researcher attributes the lack of significance in the data collected in the study to the ambitiousness of the survey. The survey was developed from the literature reviewed in chapter two and was intended to be very thorough in its evaluation of the child. The researcher does believe that the survey was a valid measure and was effectively based on the literature. However, the survey was quite long and this alone may have been a deterrent to the parents who received the packages. Not only was the survey long, but it also required careful reading and occasionally long written answers to be given by the parent completing the form. Out of 236 packages that were sent out, only 50 were returned to the researcher, indicating some element of dissatisfaction on the part of the recipient.

The area of gastrointestinal problems and young children with pervasive developmental disorders is new to the fields of science and medicine. Pervasive Developmental Disorder is a complex condition, and no cause or sole course of treatment has been established thus far. The literature available in this area of investigation is not only intriguing, but may prove to be promising in the near future. More research is

needed before a relationship can be established between the two variables. The researcher believes the survey demonstrates the vast amount of information that needs to be covered in future investigations, and also believes that the information collected in the study does add to the existing body of knowledge.

Implications for Future Research

- Develop a survey that limits the focus on behavior. For example, only look at the indications of eating behaviors on the possible existence of a gastrointestinal condition; or only sleeping behaviors; or only toileting behaviors.
- Identify a group of children that are being given care for an established feeding problem, and use this population to investigate a possible connection between the nature of the gastrointestinal problems and the behaviors exhibited by the child.
- Develop a survey that is more simplistic in nature, but is still comprehensive in its evaluation. Perhaps limit the focus of the survey; instead of incorporating all of the pertinent literature at one time, do this in steps.

Appendix A

Final form of the survey

Rowan University
Pervasive Developmental Disorders Questionnaire

Today's Date: _____ Child's Date of Birth: _____

Child's Sex: F M

Child's age when first diagnosed: _____

Please identify the diagnosis given by a doctor by placing a check mark **in front** of the title:

Autistic disorder Rett's disorder Childhood Disintegrative disorder

Asperger's disorder PDD Not Otherwise Specified

Your relationship to this child (please circle one):

Mother Father Grandparent Other _____

Please circle ALL responses that best answer each question.

1. Was your child breastfed? Yes No

If yes, how long did you breastfeed your child? _____

2. If you did not breastfeed your child, please circle the reason (you may circle more than one)

Was not convenient	Tried it but didn't work	Maternal medical problems	My child had trouble latching on	Child had problem with weight gain	Child had hydration problems	Other (please describe)
-----------------------	-----------------------------	---------------------------------	--	--	------------------------------------	-------------------------------

3. Did your child switch formulas as a baby? Yes No

If the answer is "yes" please identify why and if it helped (be specific)

4. At what age did your child begin eating food?

5. How would you describe your child's eating at 1 year of age?

Excellent Very Good Good Fair Poor

6. Does your child have unusual or unique eating habits? Yes No

If you answered "yes", please give an example or describe these behaviors as clearly as possible

7. Does your child have a feeding problem? Yes No

If you answered "yes", please describe this problem as clearly as possible

8. Does your child have cravings for certain foods? Yes No

If so, which foods?

**Rowan University
Pervasive Developmental Disorders Questionnaire**

9. Does your child have a strong dislike for certain foods? Yes No

If so, which foods?

10. Does your child have excessive thirst? Yes No

11. Does your child gag? Yes No

If you answered "yes" to this question, please circle all of the following that apply:

During Meals:	After	End of	When	No observed
Start of meal	meals	meals	doing an	patterns
Middle of meal			activity	
End of Meal			(running,	
Throughout meal			jumping)	
Only on foods child doesn't like				

12. Does your child eat non-foods (examples: sand, earth, paper, soap)? Yes No

If yes, please list non-food items that your child eats or attempts to eat.

13. Does your child have any food allergies or foods that they cannot tolerate? Yes No

Please identify these foods.

14. How do you know that your child does not tolerate these foods? (what happens)

15. Has your child been tested for any food allergies? Yes No

16. Does your child have non-food allergies? Yes No
Please list them

17. Has your child been tested for any non-food allergies? Yes No

18. Does your child exhibit gestures that indicate abdominal pain (holding or rubbing stomach, stretching, leaning over, excessive standing, won't sit down)?

Most of the day	A few times a day	2-6 times a week	Less than once a week	Don't Know
--------------------	----------------------	---------------------	-----------------------	------------

19. How often does your child's stomach appear bloated or hard and round (swollen or his/her waistband bothers them)?

Most of the day	A few times a day	2-6 times a week	Less than once a week	Don't Know
--------------------	----------------------	---------------------	-----------------------	------------

**Rowan University
Pervasive Developmental Disorders Questionnaire**

31. Does your child work to pass their bowels (spends prolonged time in the bathroom, goes off in the corner, or pushes hard)? Yes No

32. Does your child complain of headaches? Yes No

33. Are you aware of your child waking up in the night? Yes No

If so, how often are you aware of this occurring?

More than two times a night	1 – 2 times a night, most nights	1-2 times a night; for 3-4 nights a week	Less than 3 times a week on average	Rarely
-----------------------------	----------------------------------	--	-------------------------------------	--------

34. If your child awakens during the night, does he/she come to you or look for comfort?

Never Every time Most of the time Sometimes Rarely

35. Does your child use his/her finger to put pressure on or near his/her eyes?

No	Twice a week or less	Every other day	Once a day	More than once a day	Don't Know
----	----------------------	-----------------	------------	----------------------	------------

36. Does your child engage in head banging or head hitting?

No	Twice a week or less	Every other day	Once a day	More than once a day	Don't Know
----	----------------------	-----------------	------------	----------------------	------------

37. Does your child hit his/her ears?

No	Twice a week or less	Every other day	Once a day	More than once a day	Don't Know
----	----------------------	-----------------	------------	----------------------	------------

If your child hits his/her ears, circle all that apply to any of the following choices:

Through-out the day	Only during meals	After meals	After being given a demand
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38. How often has your child received Secretin?

Never	Once	Twice	Three times	More than three times
-------	------	-------	-------------	-----------------------

39. How often does your child make eye contact with you?

Never	Rarely	Sometimes	Often	Most of the time
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40. How frequently has your child been treated with antibiotics over the course of the last year?

Never	Once	2 – 3 times	4 – 6 times	7 or more times
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Rowan University
Pervasive Developmental Disorders Questionnaire

41. Did your child receive a measles immunization shot? Yes No

At what age did they receive the shot?

42. Has your child had a yeast infection? (oral thrush, candida, diaper rash) Yes No

43. When and why did you first become concerned about your child's development?

44. Does your child have asthma or reactive airway disease? Yes No

45. Does your child have eczema? Yes No

46. Have you ever sought help for your child's feeding problems? Yes No

If "yes", please identify the type of care provider from whom you sought help.

47. List all of the foods that your child eats in each of the four food groups: meats and fish; fruits and vegetables; breads and cereal; and dairy. *Please list your answers on the bottom of this page or the back of this sheet.*

Appendix B

Copy of the approval form from the Rowan Institutional Review Board

RECEIVED

OCT 0 6 2000

Appendix C

INSTITUTIONAL REVIEW BOARD
DISPOSITION FORM GRANT DEVELOPMENT OFFICE

Jennifer Gelsinger
Principal Investigator
1166 Bibbs Rd. Apt #11
Address of Principal Investigator
Roorhees, N.J. 08043
City, State, and Zip Code
856-772-6515
Telephone # Fax # e-mail address

Mary Louise Kerwin, Ph.D.
Co-Principal Investigator (if applicable)
Rowan University
Address of Co-Principal Investigator
Psychology Dept.
City, State, and Zip Code
856-256-4500 ext-3521
Telephone # Fax # e-mail address

TITLE OF RESEARCH: Prevalence of gastrointestinal symptoms in children with autism.

ADMINISTRATIVE DISPOSITION - DO NOT WRITE BELOW THIS LINE

Your claim for exemption for the research study identified above has been reviewed. The action taken is indicated below:

- APPROVED FOR EXEMPTION AS CLAIMED: CATEGORY #
Note: Anything that materially changes the exempt status of this study must be presented to the IRB for approval before the changes are implemented. Such modifications should be sent to the IRB Office at the address above.
- APPROVED FOR EXEMPTION - BUT NOT AS CLAIMED. Your claim for exemption does not fit the criteria for exemption designated in your proposal. However, the study does meet the criteria for exemption under CATEGORY #
- A determination regarding the exempt status of this study cannot be made at this time. Additional information is required.
- Your proposal does not meet the criteria for exemption, and a full review will be provided by the IRB.

EXPEDITED REVIEW: [checked] Approved [] Denied

FULL REVIEW: [] Approved [] Approved with modifications [] Denied

DENIED: []

Mary J. Gaus
Chair, IRB

[Signature]
Co-Chair, IRB

Date 10-11-00

Date 10-11-2000

Appendix C

All original materials: instruction form, consent form, cover letter, and survey

Instructions for completing the material enclosed in this package:

- Read and sign the consent form
- Send the Consent form back in the white, self-addressed, stamped envelope
- If you would like further information on this study, please complete the bottom portion of the cover letter, detach, and send it back, along with the Consent form, in the self-addressed, stamped envelope.
- Please complete the questionnaire in its entirety, and send it back in the large, self-addressed, stamped envelope (the one in which you received all of the materials).

If you have already completed this questionnaire, please do NOT do so again.

Informed Consent Form Questionnaire

Investigators: *Jennifer Gelsinger and Mary Louise Kerwin, Ph.D.*

Affiliation: *Rowan University*

Date:

We are trying to understand more about the eating and sleeping habits of children diagnosed with Pervasive Developmental disorders, and how these habits may or may not relate to the way these children behave. We would like you to take a few minutes to complete this questionnaire regarding the behavior, eating, and sleeping patterns of your child.

We anticipate little risk or discomfort to you. The data and information gathered during this study will be kept in strictest confidence. Your name will never be associated with any of your responses. Your participation is completely voluntary, and you may withdrawal at any time without penalty.

If you have any questions concerning this study you may ask them now or you may contact Dr. Mary Louise Kerwin at (856) 256-4500, ext.3521.

I _____ affirm that I have read and understand the above statement and voluntarily consent to participate in this study.

Name: _____

Date: _____

Please Note:

If you have already completed this questionnaire please do NOT do so again.

October 2, 2000

Dear Parent or Guardian,

My name is Jennifer Gelsinger, and I am a student in the Master's Program for School Psychology at Rowan University. As the technology of our country continues to advance, the benefits of science and medicine are coming together to present us with amazing opportunities to better meet the needs of those individuals who suffer with various degrees of illness and disability. The purpose of this study is to learn more about the eating and sleeping habits of children diagnosed with Pervasive Developmental Disorders, and how these habits may or may not relate to the behavior of these children.

I am conducting this study for the purpose of completing my Master's Thesis. All participation in this study is voluntary, and you may withdrawal at any time without penalty. The questionnaires will be numerically coded, and all information will be kept in strict confidence. Your names will not be used nor will you be identified in any way. You are not required to answer any question that causes you any level of discomfort.

Please complete this questionnaire if your child has been diagnosed by a doctor with one of the following conditions; Autistic Disorder, Rett's Disorder, Asperger's Disorder, Childhood Disintegrative Disorder, or Pervasive Developmental Disorder Not Otherwise Specified. Please answer each question on the questionnaire as honestly and accurately as you can. Please send the completed questionnaire back in one of the self-addressed, stamped envelopes that were provided for you in the packet. If you would like additional information about the nature of this study, please complete the bottom portion of this letter and return it in the other self-addressed, stamped envelope.

I am the principal investigator and can be reached at (856) 772- 6515; Dr. Mary Louise Kerwin, Ph.D. is my faculty sponsor, and she can be reached at (856) 256- 4500, ext. 3521. Please note the consent form included in this packet. Thank you.

Sincerely,

Jennifer Gelsinger

If you would like to receive more information about the nature of this study or the results of this study, please sign below, detach this section and mail it back in the self-addressed stamped envelope included in this package.

_____ YES, I would like further information on this study and its results.

Signature: _____

Name: _____

Address: _____

Rowan University
Pervasive Developmental Disorders Questionnaire

Today's Date: _____ Child's Date of Birth: _____
 Child's Sex: F M
 Child's age when first diagnosed with autism: _____

Your relationship to this child (please circle one):
 Mother Father Grandparent Other _____

Please circle ALL responses that best answer each question.

1. Was your child breastfed? Yes No

If yes, how long did you breastfeed your child? _____

2. If you did not breastfeed your child, please circle the reason (you may circle more than one)

Was not convenient	Tried it but didn't work	Maternal medical problems	My child had trouble latching on	Child had problem with weight gain	Child had hydration problems	Other (please describe)
--------------------	--------------------------	---------------------------	----------------------------------	------------------------------------	------------------------------	-------------------------

3. Did your child receive only breast milk or was he/she given a bottle?

Only breast milk	Breast milk with formula	Breast milk and juice by bottle	Breast milk and water by bottle
------------------	--------------------------	---------------------------------	---------------------------------

4. Did your child switch formulas as a baby? Yes No

If the answer is "yes" please identify why and if it helped (be specific)

5. Did your child go directly from breastfeeding to either of the following? Drinking from a bottle Drinking from a cup

6. Did your child experience any trouble going from breastfeeding to a bottle or a cup? Yes No

If you answered "yes", please explain.

7. At what age did your child begin eating food?

8. How would you describe your child's eating at 1 year of age?

Excellent	Very Good	Good	Fair	Poor
-----------	-----------	------	------	------

9. Does your child have unusual or unique eating habits? Yes No

If you answered "yes", please give an example or describe these behaviors

**Rowan University
Pervasive Developmental Disorders Questionnaire**

as clearly as possible

10. Does your child have a feeding problem? Yes No

If you answered "yes", please describe this problem as clearly as possible

11. Does your child have cravings for certain foods? Yes No

If so, which foods?

12. Does your child have a strong dislike for certain foods? Yes No

If so, which foods?

13. Does your child have excessive thirst? Yes No

14. Does your child gag? Yes No

If you answered "yes" to this question, please circle all of the following that apply:

During Meals:	After	End of	When	No observed
Start of meal	meals	meals	doing an	patterns
Middle of meal			activity	
End of Meal			(running,	
Throughout meal			jumping)	
Only on foods child doesn't like				

15. Does your child eat non-foods (examples: sand, earth, paper, soap)? Yes No

If yes, please list non-food items that your child eats or attempts to eat.

16. Does your child have any food allergies or foods that they cannot tolerate? Yes No

Please identify these foods.

17. How do you know that your child does not tolerate these foods? (what happens)

18. Has your child been tested for any food allergies? Yes No

19. Does your child have non-food allergies? Yes No
Please list them

20. Has your child been tested for any non-food allergies? Yes No

21. Does your child exhibit gestures that indicate abdominal pain (holding or rubbing stomach, stretching, leaning over, excessive standing, won't sit down)?

**Rowan University
Pervasive Developmental Disorders Questionnaire**

Most of the day	A few times a day	2-6 times a week	Less than once a week	Don't Know
-----------------	-------------------	------------------	-----------------------	------------

22. How often does your child's stomach appear bloated or hard and round (swollen or his/her waistband bothers them)?

Most of the day	A few times a day	2-6 times a week	Less than once a week	Don't Know
-----------------	-------------------	------------------	-----------------------	------------

23. How often does your child rub, stroke, or point to their neck or upper chest area?

Most of the day	A few times a day	2-6 times a week	Less than once a week	Don't Know
-----------------	-------------------	------------------	-----------------------	------------

24. How much does your child vomit on average?

More than once a day	Once a day	3 times a week	Twice a week or less	Don't Know
----------------------	------------	----------------	----------------------	------------

25. Did your child vomit frequently in the past, but no longer does? Yes No

26. Does your child regurgitate, and then swallow it down? Yes No

27. Does your child burp or belch frequently? Yes No

If the answer is "yes" to this question, please identify how often this occurs on average

More than once a day	Once a day	3 times a week	Twice a week or less	Don't Know
----------------------	------------	----------------	----------------------	------------

28. How often does your child move his/her bowels in a week?

More than once a day	Once a day	3 times a week	Twice a week or less	Don't Know
----------------------	------------	----------------	----------------------	------------

29. How often does your child have fecal accidents?

More than once a day	Once a day	Every other day	Twice a week or less	Don't Know
----------------------	------------	-----------------	----------------------	------------

30. How often does your child have urinary accidents?

More than once a day	Once a day	Every other day	Twice a week or less	Don't Know
----------------------	------------	-----------------	----------------------	------------

31. What is the consistency of your child's bowels?

Very hard	Formed	Soft, but	Soft and loose	Don't Know
-----------	--------	-----------	----------------	------------

Rowan University
Pervasive Developmental Disorders Questionnaire
 formed

32. How would you describe the size of your child's bowel movement?

Small Pebble size Normal Large balls Don't Know

33. How often does your child pass gas?

Never Rarely Often Most of the time Don't Know

34. Does your child have frequent or chronic loose stools (not during viral illness)?

Yes No

35. Does your child work to pass their bowels (spends prolonged time in the bathroom, goes off in the corner, or pushes hard)?

Yes No

36. Does your child complain of headaches?

Yes No

37. Are you aware of your child waking up in the night?

Yes No

If so, how often are you aware of this occurring?

More than two times a night 1 – 2 times a night, most nights 1-2 times a night; for 3-4 nights a week Less than 3 times a week on average Rarely

38. If your child awakens during the night, does he/she come to you or look for comfort?

Every time Most of the time Sometimes Rarely Never

39. Does your child use his/her finger to put pressure on or near his/her eyes?

More than once a day Once a day Every other day Twice a week or less Don't Know

40. Does your child engage in head banging or head hitting?

More than once a day Once a day Every other day Twice a week or less Don't Know

41. Does your child hit his/her ears?

More than once a day Once a day Every other day Twice a week or less Don't Know

If your child hits his/her ears, circle all that apply to any of the following choices:

**Rowan University
Pervasive Developmental Disorders Questionnaire**

Through-out the day	Only during meals	After meals	After being given a demand
------------------------	----------------------	-------------	----------------------------------

42. How often has your child received Secretin?

Never	Once	Twice	Three times	More than three times
-------	------	-------	-------------	--------------------------

43. How often does your child make eye contact with you?

Never	Rarely	Sometimes	Often	Most of the time
-------	--------	-----------	-------	------------------

44. How frequently has your child been treated with antibiotics over the course of the last year?

Never	Once	2 – 3 times	4 – 6 times	7 or more times
-------	------	-------------	-------------	-----------------

45. Did your child receive a measles immunization shot?

Yes	No
-----	----

At what age did they receive the shot?

46. Has your child had a yeast infection? (oral thrush, candida, diaper rash)

Yes	No
-----	----

47. Please identify any medications that your child takes on a regular basis (those prescribed by a doctor)

48. Please identify any “over the counter” medications that your child takes on a regular basis (examples: pepcid, tylenol, sinus, pepto-bismol, benedryl)

49. When and why did you first become concerned about your child’s development?

50. Does your child have asthma or reactive airway disease?

Yes	No
-----	----

51. Does your child have eczema?

Yes	No
-----	----

52. Have you ever sought help for your child’s feeding problems?

Yes	No
-----	----

If “yes”, please identify the type of care provider from whom you sought help.

53. List all of the foods that your child eats in each of the four food groups:

Meats and fish:

Rowan University
Pervasive Developmental Disorders Questionnaire

Fruits and vegetables:

Breads and cereals:

Dairy:

Appendix D

Follow-up letter given to parents of the pre-school location

January 22, 2001

Dear Parent or Guardian,

On November 21 your child came home from school with a packet containing a survey, a consent form, and a cover letter with some basic instructions on how to complete all of the forms in the packet. The survey is a tool for collecting data for my thesis.

I realize that the holiday season is hectic, and that my timing may have been bad. So, the purpose of this letter is to ask you to take a few moments to complete the survey and return it in the self-addressed, stamped envelope that was provided for you in the packet, if you have not already done so. Without this data it is impossible for me to complete my thesis. I appreciate your time and effort in completing the survey.

If you have misplaced your packet please ask your child's teacher for another one. I have left extra packets with the school's coordinator. Thank you.

Sincerely,

Jennifer Gelsinger

Appendix E

Revised cover letter

January 28, 2001

Dear Parent or Guardian,

My name is Jennifer Gelsinger, and I am a student in the Master's Program for School Psychology at Rowan University. As the technology of our country continues to advance, the benefits of science and medicine are coming together to present us with amazing opportunities to better meet the needs of those individuals who suffer with various degrees of illness and disability. The purpose of this study is to learn more about the eating and sleeping habits of children diagnosed with Pervasive Developmental Disorders, and how these habits may or may not relate to the behavior of these children.

I am conducting this study for the purpose of completing my Master's Thesis. All participation in this study is voluntary, and you may withdrawal at any time without penalty. The questionnaires will be numerically coded, and all information will be kept in strict confidence. Your names will not be used nor will you be identified in any way. You are not required to answer any question that causes you any level of discomfort.

Please complete this questionnaire if your child has been diagnosed by a doctor with one of the following conditions; Autistic Disorder, Rett's Disorder, Asperger's Disorder, Childhood Disintegrative Disorder, or Pervasive Developmental Disorder Not Otherwise Specified. Please answer each question on the questionnaire as honestly and accurately as you can. Please send the completed questionnaire back in one of the self-addressed, stamped envelopes that were provided for you in the packet. If you would like additional information about the nature of this study, please complete the bottom portion of this letter and return it in the other self-addressed, stamped envelope.

I am the principal investigator and can be reached at (856) 772- 6515; Dr. Mary Louise Kerwin, Ph.D. is my faculty sponsor, and she can be reached at (856) 256- 4500, ext. 3521. Please note the consent form included in this packet. Thank you.

Sincerely,

Jennifer Gelsinger

Instructions for completing materials:

- Read and sign consent form; than send it back in the white, self-addressed, stamped envelope
- If you choose, complete the bottom portion of this letter and send it back with the consent form
- Complete the survey and send it back in the **same envelope** along with the consent form and bottom portion of this letter (optional).
- **If you have already completed this survey, please do NOT do so again.**

If you would like to receive more information about the nature of this study or the results of this study, please sign below, detach this section and mail it back in the self-addressed stamped envelope included in this package.

_____ YES, I would like further information on this study and its results.

Signature: _____

Name: _____

Address: _____

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