

The impact on the family of a child's feeding and swallowing problems: Associations with parental stress, and children's daily functional activities

by

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B.S. in Communication Sciences and Disorders, University of Cincinnati, 2009

Submitted to the Graduate Faculty of

School of Health and Rehabilitation Sciences in partial fulfillment

of the requirements for the degree of

M.S. in Speech-Language Pathology

University of Pittsburgh

2011

UNIVERSITY OF PITTSBURGH
SCHOOL OF HEALTH AND REHABILITATIVE SCIENCES

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Introduction: Eating and drinking are essential components of everyday life. Adequate nutrition and hydration need to be maintained for growth and development. Many social gatherings/events revolve around eating and drinking. When something goes wrong with any part of eating or drinking it is called dysphagia. Children right through to adults and the elderly can have problems with eating and drinking. Problems eating or drinking in children could impact the family and create more stress for parents.

Methods: Data from three scales including the Parenting Stress Index-Short Form, The Functional Status II(R) and the Pediatric Feeding and Swallowing Family Impact Scale-Revised were provided and analyzed. Data were analyzed using a Pearson product-moment correlation. Demographic information was provided as well. Student's t-tests were done on groups of participants to assess if there was a difference in means. Spearman rank correlations were done to determine relationships between ranked groups, such as income bracket, and each of the scales. Pearson product-moment correlations were done on continuous groups and the three scales to determine relationships.

Results: A significant correlation of was found between the Parenting Stress Index-Short Form and the Pediatric Feeding and Swallowing Impact Scale-Revised. An inverse significant correlation was found between the Pediatric Feeding and Swallowing Family Impact Scale-Revised and the Functional Status II(R). Results revealed a significant inverse relationship between the Parenting Stress Index Short Form and the Functional Status II(R). A difference in

reported scores was found on the Parenting Stress Index-Short Form of children with feeding tubes and children without feeding tubes. Scores from parents of children with feeding tubes on the Pediatric Feeding and Swallowing Disorders Family Impact Scale-Revised differed versus those without a feeding tube.

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1.0 INTRODUCTION

Eating and drinking are essential for everyday life and to maintain adequate nutrition and hydration. Many social gatherings/events revolve around eating and drinking. Swallowing is the part of eating and drinking where food or drink is prepared in the mouth and then moved into the pharynx and into the esophagus. When something goes wrong with swallowing it is called dysphagia. Children right through to adults and the elderly can have problems with eating and drinking. Problems eating or drinking in children could impact the family and create more stress for parents.

1.1 NUTRITION AND HYDRATION

Nutrition is fuel for the body. Malnutrition occurs when an individual does not have the proper variety and quantity of macro- and micronutrients necessary for survival and growth. Growth can be used as an indicator of adequate nutrition (Kovar, 1997). Adequate nutrition is important early in life to gain and maintain healthy growth. Rats that were malnourished were found to not only lag behind in typical body weight, but also organ/brain weight. Lower weight was due to lack of cell division. If nourishment is re-introduced before cell division is affected body and organ weight can be restored (Winick & Noble, 1966; Winick & Rosso, 1969). Chronic malnutrition early in life can lead to several adverse effects: lowered IQ, compromised oxygenation,

interference with clotting, impaired vision, and reduced bone and tooth strength (Kovar, 1997; Stoch & Smythe, 1963).

Habilitation and rehabilitation outcomes have shown to be predicted by nutrition and hydration status (Kedlaya & Brandstater, 2002). One of the major outcomes of long-term dehydration in children is too much sodium in body fluids or hypernatremia. Persistent and severe dehydration could lead to too much acid in body fluids (acidosis) or the heart being unable to supply enough blood to the body. This could lead to organ damage (Escobar, et al., 2007).

1.2 DYSPHAGIA

Dysphagia is an impairment in swallowing. Structures from the lips to the top of the stomach may be involved (Leslie, Carding, & Wilson, 2003). Dysphagia is a major cause of poor hydration and malnutrition in the elderly and in children (Kedlaya & Brandstater, 2002). A feeding disorder includes a problem with the placement of food in the mouth, a difficulty in manipulation of food before a swallow is started and a difficulty moving food in the mouth backward with the tongue. In the pediatric population the term, feeding disorder, is used to describe when there is a failure to develop appropriate eating and drinking behaviors or demonstrate the appropriate use of these behaviors (American Speech-Language-Hearing Association 2001). Children with feeding and swallowing disorders are especially at risk for nutrition-related problems, such as those mentioned above (Kovar, 1997).

1.3 PEDIATRIC DYSPHAGIA

The number of children with feeding and swallowing problems is on the rise. The prevalence of feeding problems is estimated to be between 25-45% in typically developing children (Lefton-Greif & Arvedson, 2007). Children with developmental delays are more at risk for feeding problems putting the prevalence in this population as high as 80% (Lefton-Greif & Arvedson, 2008). The prevalence of pediatric dysphagia is unknown at this time. Preterm infants with low or very low birth weight, infants with cardio-respiratory conditions and children with neurological traumas also have an increased risk for dysphagia. Due to an increase in advanced technology the survival rates of these children have gone up. These factors could contribute to the rise in children with dysphagia (Arvedson, 2008; Lefton-Greif & Arvedson, 2007; Miller & Willging, 2003). There has been a 20% increase in the percentage of infants delivered preterm since 1990 and over a 20% increase of infants born with low birth weight in the past 20 years (Lefton-Greif & Arvedson, 2007).

A difference in considerations for assessment and management of children with feeding and swallowing problems must be made from adults (American Speech-Language-Hearing Association 2001). There is a difference in the anatomical structures important for feeding and swallowing in children. Etiologies of feeding and swallowing problems differ in children than in adults. Children are not able to talk about their symptoms in the same manner that most adults are able to describe their feeding and swallowing problem. Lastly children are developing and their feeding and swallowing problem will change more over time (American Speech-Language-Hearing Association 2001).

Symptoms of dysphagia in general may include food refusal, coughing or choking. Inflexible/selective food choices, disruptive behavior during mealtime, and failure to master

developmentally normative feeding skills are symptoms more common to pediatric dysphagia.

Signs of pediatric dysphagia may include non-optimal growth, failure to thrive or negative feeding behaviors (Davies, et al., 2006). Negative feeding behaviors are the most common presenting sign of pediatric dysphagia (Davies, et al., 2006). Examples of negative feeding behaviors are inability to accept or eat an assortment of foods and refusing to accept or eat certain foods (Babbitt, et al., 1994). A child may be unable to accept or eat an assortment of foods due to neuromuscular, metabolic or skeletal dysfunction. A child may refuse food because of a psychosocial dysfunction (Babbitt, et al., 1994).

There are various etiologies that can contribute to pediatric feeding and swallowing issues. Etiologies can exist individually or be multidimensional in nature. A high rate of dysphagia is seen in people with cerebral palsy. It is especially high in children who have spastic quadriplegia or extrapyramidal cerebral palsy (Arvedson, 2008; Lefton-Greif & Arvedson, 2007, 2008; Prasse & Kikano, 2009).

1.4 THE EFFECTS OF CHILDHOOD ILLNESS ON THE FAMILY

Children with chronic illness may create an emotional and psychological burden on the family (Jessop & Stein, 1985). Daily care of children with chronic illness has been found to be a burden as well. This burden usually falls on the family (Wallander & Varni, 1998) and (Rodenburg, Meijer, Dekovic, & Aldenkamp, 2007). Dysfunction within the family may result, which in turn can affect a child psychologically (Jessop & Stein, 1985).

Increased levels of parenting stress have been found in families with children who have conditions such as cerebral palsy and Type 1 diabetes when compared to families with typical

children (Britner, Morog, Pianta, & Marvin, 2003; Powers, et al., 2002). Higher levels of parenting stress were correlated with lower behavioral control or higher lax parenting, and higher levels of psychological control. Psychological control is when a parent tries to change a child's behavior by intervening in the child's emotional and psychological developmental needs (Rodenburg, et al., 2007).

Parents of children with epilepsy reported higher parenting stress in association with several other factors (Rodenburg, et al., 2007). A lower quality parent-child relationship was associated with high parenting stress and lower perception of the child's functional status. Parents with higher stress provided lower parental support defined as not providing a warm, safe and affectionate environment (Rodenburg, et al., 2007).

Parents' perceptions of the degree to which a child can function in daily living activities despite his or her health condition, or his/her functional status (Bleil, Ramesh, Miller, & Wood, 2000), have been found to be associated with higher levels of parenting stress by parents of children with epilepsy (Rodenburg, et al., 2007). In children with asthma lower caregiver perception of functional status also influenced the relationship between the child and his or her primary caregiver (Bleil, et al., 2000).

Families of children with chronic illness may experience high healthcare costs and an increase in amount of healthcare a child may need. The high costs and amount of healthcare a child may need have been found to be associated with higher parenting stress (Strauss & Cassell, 2009). It has been found that families of children with cranio-facial abnormalities may experience barriers when trying to access care for their child (Strauss & Cassell 2009). Worrying about costs and making sure the child receives all the necessary care could add stress to parenting.

1.5 DYSPHAGIA EFFECT ON QUALITY OF LIFE

Dysphagia affects quality of life. The burden of dysphagia has negative social and psychological consequences. This burden can lead to an increase in isolation and a decrease in self-esteem (Ekberg, Hamdy, Woisard, Wuttge-Hannig, & Ortega, 2002). Eating and drinking are often the center of social interactions, holidays and family congregations. Not being able to fully participate can lead to embarrassment and lower dignity (Ekberg, et al., 2002). Many patients with dysphagia do not believe they can be helped. This belief may lead to patients not actively talking to health professionals about their dysphagia or the isolation and psychological burden it causes. The combination of social and psychological handicaps dysphagia may cause could lead to depression (Ekberg, et al., 2002). The feeling of not being able to talk about this to health professionals may also contribute to feelings of depression (Ekberg, et al., 2002).

1.6 PEDIATRIC DYSPHAGIA EFFECT ON PARENTING STRESS/FAMILY

Pediatric dysphagia also affects parenting stress and families. Negative feeding behaviors may lead to a negative relationship between the child and caregiver. There is a bonding experience a parent feels during feeding and mealtimes. When this time is a negative experience a parent may feel guilt. The higher stress found in parents of children with chronic illness further lower the quality of parent-child relationship. It is important to look at parenting stress of children with feeding and swallowing issues based on the perception of their child's functional health.

There are economic and psychological effects of having a child with a gastrostomy feeding tube. Families with children who had gastrostomy tubes had over twice the financial

costs than those with children with no tubes (Heyman, et al., 2004). It did not matter if a child had a tube or not, parents with chronically ill children experienced similar feelings of depressive mood and quality of life (Heyman, et al., 2004).

1.7 AIMS

Quality of life can be looked at by analyzing the relationship between pediatric feeding and swallowing problems impact on the family, parenting stress and perception of functional status. The aim of this study was to investigate if there is an association in a sample of 100 caregivers of children with feeding and swallowing problems between

- 1.) Parental stress
- 2.) A child's ability to perform daily living activities and
- 3.) The impact of feeding and swallowing issues on the family.

An association found between each of these factors will provide more information on parental stress and what impacts the family. This information can help during intervention. Clinicians could use this information to help clients cope with their stress and the stressors that come along with having a child with dysphagia.

2.0 METHODS

2.1 PROCEDURE

De-identified data sets were provided to the researcher for analysis, along with demographic information of the participants. The data sets included scores from the Parenting Stress Index-Short Form, the Functional Status-II(R) and the Pediatric Feeding and Swallowing Disorders Family Impact Scale. These tools are described below. The demographic information was analyzed to identify frequency of specific descriptive information. The scores of the three tools were analyzed to identify and describe the associations between these three factors and also with specific demographic information.

2.2 PARTICIPANTS

Participants were recruited from a large metropolitan pediatric hospital. Attempts were made to contact the families of all patients (age 1 year to 4 years 11 months) seen through an Interdisciplinary Feeding Team during 2008 and 2009. Families were contacted via telephone and were also recruited through the Division of Speech Pathology. A total of 130 families were contacted and verbally consented to receive information on the study.

The participants' were parents or caregivers of children that had been evaluated or treated by the children's hospital feeding and swallowing team. Once verbally consented, packets containing written consent documentation, the three questionnaire tools, and the demographic information questionnaire were sent to the parent or caregiver. One hundred families consented to participate in the study and returned their packets.

2.3 TOOLS

2.3.1 Parenting Stress Index-Short Form

The Parenting Stress Index-Short Form (Abidin, 1995) is a 36 item questionnaire to measure parenting stress in a quick and concise manner. The Parenting Stress Index-Full Version was first developed in 1976 based on the theoretical model that parental stress is based on noticeable child characteristics, parent characteristics, and situational variables of the role of being a parent ("The National Child Traumatic Stress Network," 2005). Examples of child characteristics are distractibility, hyperactivity, adaptability, demandingness, mood and acceptability. Competence, isolation, attachment, health, depression and spouse are examples of parent characteristics and situational variables.

The short form has 36 items taken directly from the full-length form. These items were chosen based on a factor analysis in which three sub-groups were found. These are *parental distress*, *parent-child dysfunctional interaction*, and *difficult child* ("The National Child Traumatic Stress Network," 2005). The short form is designed to take around 10 minutes to complete for parents of children 0 years to 12 years of age. Scores range from 36 to 180 with

higher scores correlating to more stress. Many other studies have been conducted to demonstrate validation of the scale ("The National Child Traumatic Stress Network," 2005). This tool will be referred to as the STRESS scale in this research project.

2.3.2 Functional Status II (R)

The Functional status II (R) is a revised version of the Functional Status I that was used to measure individual child health status and characterize populations (Stein & Jessop, 1990). This scale was first developed to look at child health in children with long-term health conditions (Stein & Jessop, 1990). The scale contains a long form of 43 items that are broken up into General Health and Stage Specific factors for age groups within the range 0 to 16 years. The age groups are 0 to 2 years (responsiveness), 2 to 3 years (activity) and then 4 years and up (interpersonal functioning). Examples of what may be included in responsive are if the child eats well, sleeps well, occupy self, smile, coo, or babble. Activity component examples are responsiveness factors plus other factors such as temper tantrums, trouble with tasks, afraid or not of new situations or playing games. Interpersonal function includes the above mentioned information and then also participating in exercise, dress self, absence from school and other related questions (Stein & Jessop, 1990). Each question includes two factors: whether a child has difficulty doing specific behaviors, and whether the difficulty was due to a health problem (Stein & Jessop, 1990).

The short version includes 14 items from a common core across the entire age span. The questions contain concepts that are related to communication, mood, energy, play, sleep, eating, and toileting. These concepts are addressed in a child's normal social role at home, in the neighborhood, at school, during leisure, work, and rest (Stein & Jessop, 1990). Scores range

from 0 to 209. The scale was found to be reliable and valid (Stein & Jessop, 1990). In a study testing the psychometric properties among infants with extremely low birth weight, reliability and validity were found to be sound (Da Costa, Bann, Hansen, Shankaran, & Delaney-Black, 2009). This tool will be referred to as the FUNCTIONAL scale in this research project.

2.3.3 Pediatric Feeding and Swallowing Disorders Family Impact Scale-Revised

The Pediatric Feeding and Swallowing Disorders Family Impact Scale- Revised (Redle, 2007) was developed to help clinicians identify the impact feeding and swallowing problems have on the family. The tool addresses specific concerns and needs of individual families. Clinical researchers could also use this scale for outcomes measurement (Redle, 2007). Themes that emerged from previous research on caregiver concerns of children with diverse feeding and swallowing problems, feeding methods, and underlying health conditions were used to create the scale (Redle, 2007). The scale was found to be reliable and valid, but the use as a long-term outcome measure is yet to be determined (Redle, 2007).

Administration burden, or time to complete, was taken into account during the pilot study. It was found that this tool had minimal burden with a sixth grade reading level and administration time around 13 minutes with no caregivers indicating it was too long (Redle, 2007). Scoring of this scale had not yet been determined. A comparison of children with feeding and swallowing disorders and typical children revealed a large effect size. This demonstrates that there is a difference between scores from caregivers of children with feeding and swallowing disorders and caregivers of typical children (Redle, 2007). This tool will be referred to as the IMPACT scale in this research project.

2.4 DATA ANALYSIS

Participant information was analyzed using descriptive frequencies.

The relationships between the STRESS scale, FUNCTIONAL scale and IMPACT scale were analyzed using a Pearson product-moment correlation coefficient (r). A Pearson product-moment correlation is used to find the association between variables using continuous and actual scores (Schiavetti & Metz, 2006).

I used a Student's test (t) to examine if the presence of a feeding tube would affect the scores on each of the scales. A Student's t -test is used to find if there is a significant difference between the means of two groups of data (Schiavetti & Metz, 2006). There is evidence in the literature that families with children who have gastrostomy tubes have greater financial and psychological costs (please refer to section 1.6).

The effects of having a child born prematurely on each of the scales was examined using a Student's test (t). Evidence shows with advanced technology survival rates of preterm infants has risen. These infants are at a greater risk for having dysphagia (see section 1.3).

I chose to examine if the gender of the child would affect the scores on each of the scales using a Student's test (t). In the literature the difference in sex of a child has not been associated with patient or parent reported measures of family adjustment to having a child with cancer (Wallander & Varni, 1998).

I did not examine if sex of the participants would affect scores on the scales. The ratio of female to male was skewed, as 97% of the primary caregivers were female.

The relationship between race and each of the scales was examined using a Spearman rank correlation coefficient (r_s). A Spearman rank correlation is used to find associations between variables that are ranked scores or converted to ranked scores (Schiavetti & Metz,

2006). Different ethnic groups may respond differently to having a child with pediatric dysphagia. Social resources and sociodemographics were found to contribute to family burden, which could be associated with race (Stancin, Wade, Walz, Yeates, & Taylor, 2008).

A Spearman rank correlation coefficient (r_s) was used to examine the relationship between highest education level of participants and scores on each of the scales. The amount of resources and available health information a family has could be associated with adjustment of families to their child's health condition (see section 1.4) (Rodenburg, et al., 2007; Wallander & Varni, 1998). Highest education level may also be correlated with parenting stress and pediatric dysphagia impact on the family. It could be that the more educated a caregiver is the more resources and health information they may have. This may lead to higher stress, as he or she knows the worst and best possible outcomes. Not having this information may lead to higher stress due to not knowing information about their child's health condition.

Income bracket and the relationship to scores on each of the scales were examined using a Spearman rank correlation coefficient (r_s). Costs of healthcare have been found to be associated with parenting stress (refer to section 1.4). Families of children with gastrostomy tubes were found to have a higher financial burden (refer to section 1.6). The financial costs may affect the relationship between income and pediatric dysphagia impact on parenting stress or the family.

I used a Spearman rank correlation coefficient (r_s) to examine the relationship between birth order and each of the scales. Birth order was examined because it may affect the family dynamic. The severity of traumatic brain injury has been found to be associated with sibling burden although specific birth order was not looked at (Stancin, et al., 2008).

A Pearson product-moment correlation coefficient (r) was used to examine the relationship between age of the caregivers and scores on each of the scales. Coping strategies

were found to be associated with parenting stress (Rodenburg, et al., 2007). Age of caregiver may affect coping strategies.

I examined the relationship between age of the children and scores on each of the scales using a Pearson product-moment correlation coefficient (r). Burden and distress of families with children who had a traumatic brain injury were dependent on age of the child (Stancin, et al., 2008). Age of a child with a pediatric dysphagia may also moderate scores on each of the scales.

Results were accepted as statistically significant at the 5% level. This means that the probability that the results found were due to chance is just 5% (Schiavetti & Metz, 2006).

3.0 RESULTS

3.1 DEMOGRAPHIC INFORMATION

There were 100 parents or caregivers of children with feeding and swallowing disorders in this study. The age of the participants was 22 years to 55 years. Ninety-seven percent of participants were female. The majority (87%) of the participants reported race as white (see Figure 1). The 2010 Census reports that in United States of America 72.4% of the population report race as white, 12.6% as African American, 4.8% as Asian, American Indian as 0.9%, some other race as 6.2% and two or more races as 2.8% ("2010 Census Data," 2010). Participants highest education was at least high school diploma or equivalent (see Figure 2). The income of participants ranged from less than \$20,000 to more than \$100,000 (see Figure 3). Seventy-five percent of the participants were married, eight percent divorced, two percent were separated and thirteen percent were never married.

The participants' children's ages ranged from 1 year to 5 years and 54% were female. The percent of children with a tube was 41%, and 6% of the children were reported to be no food by mouth or NPO. The majority (81%) of the participants reported children's race as white (see Figure 4). Almost half of the children were second born children (see Figure 5). More than half of the children were full-term (see Figure 6).

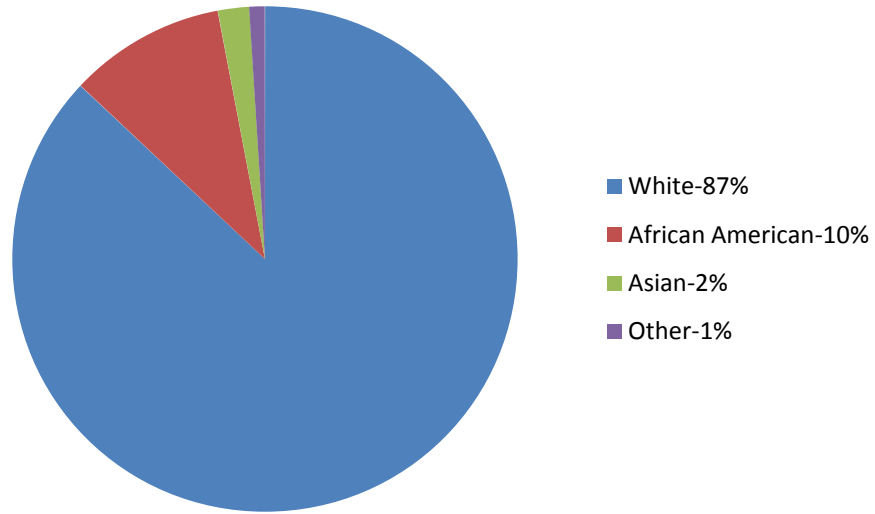


Figure 1. Reported race of the participants

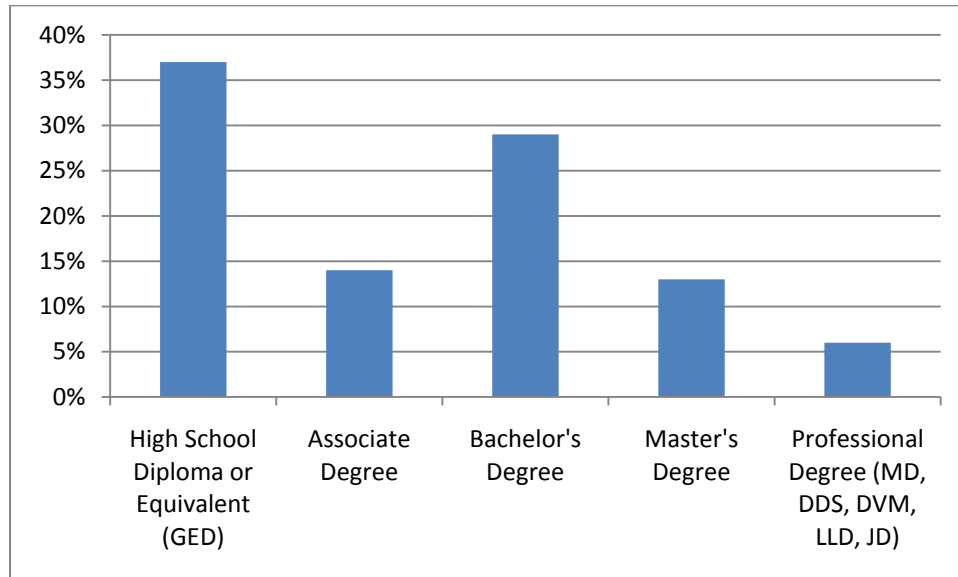


Figure 2. Education Level of Participants

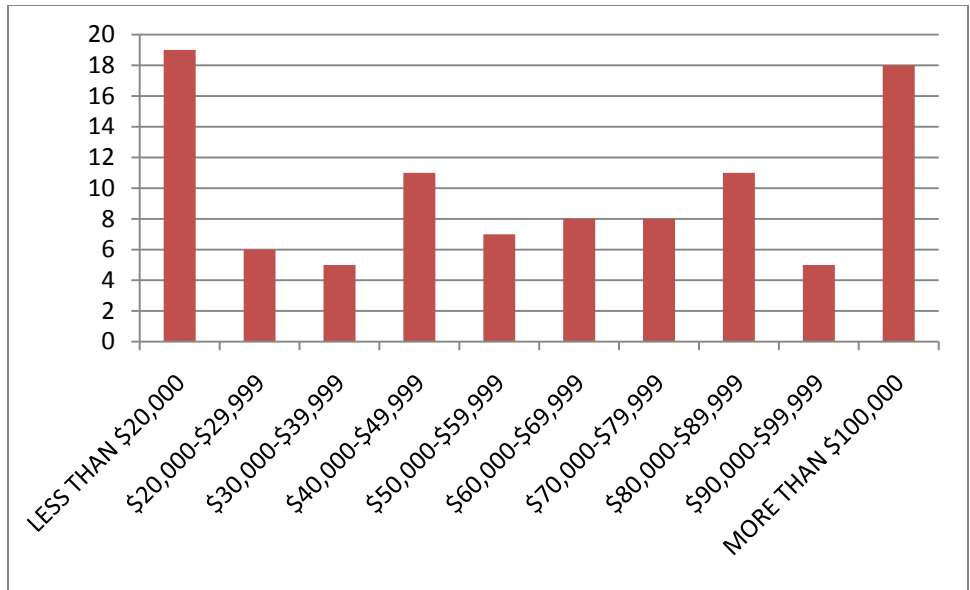


Figure 3. Income of Participants

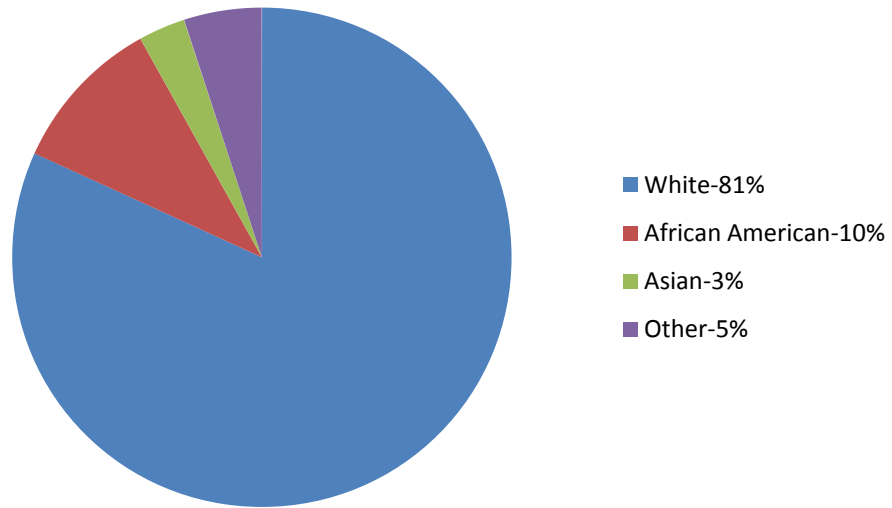


Figure 4. Race of Children

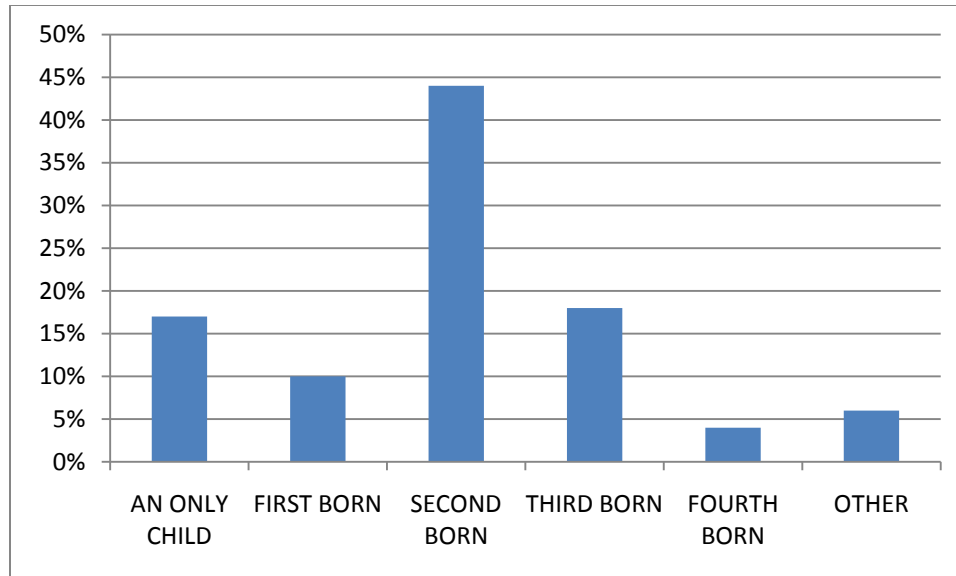


Figure 5. Birth Order of Children

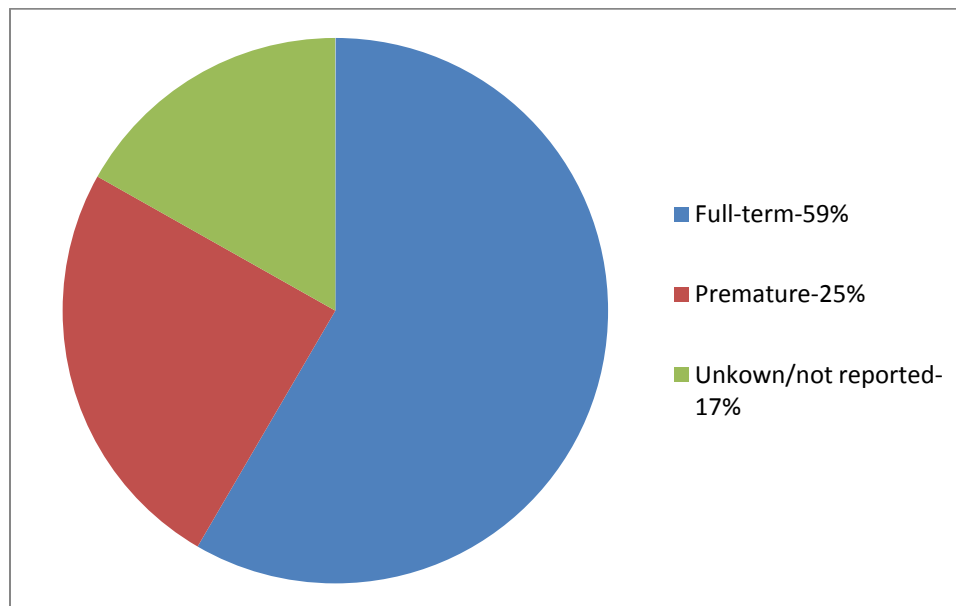


Figure 6. Birth information of Children

3.2 RELATIONSHIP OF THE SCALES

There was a positive statistically significant association between the scores on the IMPACT and STRESS scales ($n = 94$, $r = 0.553$, $p < 0.001$ level, $r^2 = 0.30$).

The correlation between the FUNCTIONAL scale and the STRESS scale was an inverse statistically significant correlation ($n = 88$, $r = -0.284$, $p = 0.007$, $r^2 = 0.08$).

A statistically significant inverse correlation was found between the IMPACT and FUNCTIONAL scales ($n = 89$, $r = -0.231$, $p = 0.029$, $r^2 = 0.05$).

There was missing data for the FUNCTIONAL and STRESS scale. Eleven percent ($n=12$) of participants did not return the FUNCTIONAL scale. The STRESS scale was not returned by six percent ($n=7$) of participants.

3.3 DIFFERENCES BETWEEN GROUPS

A significant difference was found between scores on the IMPACT scale of children with feeding tubes and those who did not have a tube (see Table 1). Scores on the STRESS scale also differed with children who had a feeding tube and children with no tube (see Table 1). Results from the FUNCTIONAL scale did not reveal a significant difference for children with a feeding tube and children without a feeding tube (see Table 1).

No significant difference was found between scores on the IMPACT, STRESS or FUNCTIONAL scales of children who were premature versus those who were not (see Table 2).

A significant difference was not found between scores on the scales of children who were male or scores for children who were female (see Table 3).

Table 1. Effect of presence of feeding tube on scores of the three scales

	median	range	mean (\pm SD)	95% confidence interval of mean differences	t (df)	significance p
STRESS						
Tube (n= 37)	102	62, 140	103 (20)	0.06, 19.5	2.0 (90)	0.049
No tube (n= 56)	87.5	48, 148	94 (27)			
IMPACT						
Tube (n= 40)	131	74, 178	131 (27)	5.31, 29.5	2.856 (96)	0.005
No tube (n= 58)	121	43, 166	114 (31)			
FUNCTIONAL						
Tube (n= 34)	93	57, 100	87 (14)	-10.0, 2.95	-1.082 (87)	0.282
No tube (n= 55)	100	43, 100	91 (15)			

Table 2. Effect of child born prematurely on scores of the three scales

	median	range	mean (±SD)	95% confidence interval of mean differences	significance t (df)	p
STRESS						
premature (n= 57)	104	55, 148	95 (22)	-18.8, 5.9	-1.045 (77)	0.299
not Premature (n= 22)	95	55, 143	102 (31)			
IMPACT						
premature (n= 57)	120.5	51, 174	123 (31)	-13.1, 16.9	0.253 (79)	0.801
not Premature (n= 24)	129	43, 177	121 (31)			
FUNCTIONAL						
premature (n= 52)	100	43, 100	91 (12)	-2.3, 12.9	1.389 (73)	0.169
not Premature (n= 23)	96	61, 100	86 (21)			

Table 3. Effect of sex of the child on scores of each of the scales

	median	range	mean (±SD)	95% confidence interval of mean differences	significance t (df)	p
STRESS						
male (n= 52)	99	48, 148	98 (25)	-9.4, 11.3	0.185 (92)	0.853
female (n= 42)	97	55, 147	97 (25)			
IMPACT						
male (n= 54)	125	58, 173	123 (29)	-10.5, 14.6	0.326 (96)	0.745
female (n= 44)	127.5	43, 178	121 (34)			
FUNCTIONAL						
male (n= 47)	96	43, 100	88 (16)	-9.7, 2.9	-1.062 (87)	0.291
female (n= 42)	96	43, 100	92 (14)			

*Scores always reported as whole numbers

3.4 RELATIONSHIPS OF RANKED GROUPS AND THE SCALES

No significant correlation was found between reported race and any of the scales (STRESS $n = 92$, $r_s = 0.039$, $p = 0.711$, FUNCTIONAL $n = 87$, $r_s = -0.045$, $p = 0.680$, IMPACT $n = 99$, $r_s = -0.048$, $p = 0.635$).

The correlation between the scales and education level of the participants was not significant (STRESS $n = 92$, $r_s = -0.140$, $p = 0.182$, FUNCTIONAL $n = 87$, $r_s = 0.119$, $p = 0.272$, IMPACT $n = 99$, $r_s = -0.006$, $p = 0.955$).

No correlations were found between the scales and income bracket of the participants (STRESS $n = 91$, $r_s = -0.006$, $p = 0.958$, FUNCTIONAL $n = 86$, $r_s = 0.186$, $p = 0.086$, IMPACT $n = 98$, $r_s = 0.049$, $p = 0.629$).

Birth order of the children did not significantly correlate to scores on the scales (STRESS $n = 92$, $r_s = 0.151$, $p = 0.151$, FUNCTIONAL $n = 87$, $r_s = -0.003$, $p = 0.979$, IMPACT $n = 99$, $r_s = 0.086$, $p = 0.398$).

3.5 RELATIONSHIPS OF CONTINUOUS GROUPS AND THE SCALES

A relationship was not found between age of the participants and the STRESS scale, the FUNCTIONAL scale or the IMPACT scale (STRESS $n = 92$, $r = 0.074$, $p = 0.481$, FUNCTIONAL $n = 87$, $r = 0.185$, $p = 0.087$, IMPACT $n = 99$, $r = 0.079$, $p = 0.438$).

There was not a significant correlation found between the scales and age of the children of the participants (STRESS $n = 94$, $r = 0.150$, $p = 0.149$, FUNCTIONAL $n = 89$, $r = -0.062$, $p = 0.562$, IMPACT $n = 98$, $r = 0.057$, $p = 0.579$).

4.0 DISCUSSION

This is the first study looking at factors of pediatric feeding and swallowing disorders such as impact on the family, parenting stress and parental perception of their child's functional status.

Results from this study indicated that there is a relationship between the impact feeding and swallowing disorders put on the family and parenting stress. The strong correlation between the IMPACT scale and the STRESS scale showed that as family impact increases parenting stress also increases. Although the correlation is large and significant there is still just 30 percent chance ($r^2=0.30$) a higher impact will have the correlated higher stress. There are factors that may lead to more impact, but help alleviate some parenting stress that account for some of the variance. An example is extra care provided to some parents may lead to a higher impact on the family, but alleviate some of the stressors put on parents. Lower levels of parenting stress were correlated with higher levels of social support, family cohesion and marital satisfaction in a study looking at parenting stress of children with epilepsy (Rodenburg, et al., 2007).

An inverse relationship between parenting stress and perceived functional status was found as a result of this study. Family impact and caregivers' perceptions of their child's functional status had a similar pattern in that in that as perceived functional status decreased family impact increased. A lower perceived functional status may correlate to these factors, because if a parent rates the ability of their child in regards to activities of daily living lower they

may feel more stress. Also if they perceive their child as having more difficulty with daily activities the family may feel more impact.

A difference was found between amount of parenting stress for caregivers of children with feeding tubes and children without feeding tubes. Parents of children with feeding tubes reported higher stress than parents of children with no tubes.

The results of this study also indicated there is a difference between the impact feeding and swallowing disorders have on families with children with feeding tubes and families of children without feeding tubes. Scores on the IMPACT scale were higher, indicating more impact for children with tubes than children without. Our findings support previous work showing that there is almost twice the economic cost and twice the amount of total care for families of children with gastrostomy tubes (Heyman, et al., 2004). This increased amount of care and economic burden could account for the higher impact found on the family.

The difference in parenting stress of parents with children who have a feeding tube versus those who do not have a tube may not be as significant as the difference in family impact due to parents knowing that with a feeding tube their child is receiving proper nutrition. Parents of children who are chronically ill may have more anxiety about their child being undernourished (Davies, et al., 2006). A difference still might exist because there are still health concerns and more care that might go along with having a feeding tube.

My results did not agree with the findings of Stancin, et al (2008) that age of the child correlates with burden and distress in parent reports of children with traumatic brain injury. They found higher stress correlated to increasing age, so the older the child the higher reported stress (Stancin, et al., 2008). I found that there was no correlation between age of the child and the amount of impact on the family or parenting stress. Unlike the study involving children with

traumatic brain injury, my population did not include school-aged children and feeding and swallowing disorders do not usually have a sudden onset. The participants in my study did not have to take into account having their child attend school, or the effects of a sudden trauma. These factors could be the reason we did not find that age was a predictor of more or less parenting stress or family impact.

The large amount of second born children in this study could be attributed to caregivers not being aware their first child can be helped or that there is something wrong. This leads to there not being as many first born children as second born. A parent then may seek help for their second born child. There may be less third born children because a caregiver may be too busy to seek help or feel they already know what to do about their child's feeding and swallowing problem. This may be why there are less fourth born children as well. Because the age of children in this study was one year to five years there would not be any fifth or sixth born children.

No other factors that we looked at correlated with impact on the family, parenting stress or functional health status. This indicates that it does not matter race, income, age, education level or sex of a child, families of children with feeding and swallowing disorders will be similarly impacted and parents will have similar stress. Everybody reacts differently to stress and chronic illness. A factor that creates impact on one person may have no impact on another. Results from this study indicate that what affects a family or parenting stress is not dependent on the above mentioned factors.

4.1 LIMITATIONS OF CURRENT RESEARCH

A correlation analysis was done on the scales meaning nothing can be said about causation of family impact, parenting stress or perceived functional status. Although some demographic factors were analyzed to find relationships of what may impact the family and parenting stress, there are more factors that need to be addressed. First of all it was not indicated who filled out the scales, only the sex. A grandparent, aunt, or family member caregiver may have more or less stress. Also it is important to know if the caregiver filling out the form was a biological parent or adoptive parent. It may make a difference if the child a caregiver is caring for is her/his biologic child.

Another factor that may influence the data is that nearly all of the reporters were female, as most primary caregivers are female. A male or father may perceive impact on the family, stress and their child's functional status differently.

Scores from a foster parent would also be important to look at for each of the scales. Having a child with dysphagia only temporarily in the home may significantly impact the amount of stress or the family.

Lastly marital status was looked at based on if married, widowed, divorced, separated or never married. It was not taken into account whether the participant was married to the mother or father of the child. Other issues affecting marital satisfaction were not taken into account. This could be another predictor of impact on the family or parenting stress.

This study demonstrated that there is a relationship between the impact of feeding and swallowing disorders on the family and parenting stress and perception of functional status. The results also indicated that having a child with a feeding tube affects families differently. No other differences were indicated in this study. This may show that the sample size was too small, or

that impact on the family and parenting stress is universal no matter race, income, education level, age of caregiver, or age of child. There also may be other factors of the characteristics of the caregivers themselves that need to be considered. Examples of such factors could be temperament, caregiver health or financial difficulties.

4.2 CLINICAL IMPLICATIONS AND FUTURE RESEARCH

Results of this study have several clinical implications for intervention purposes. First of all the IMPACT scale can be used as another tool for clinicians during evaluation in a family-centered approach to intervention. The scales can be used to help clinicians better counsel patients, gain a higher rapport with families and determine what the family needs. The results of this study can also be used to show parents that they are not alone in their stress or the impact a feeding and swallowing disorder is having on the family.

Future research needs to be done to look at how the use of the scales in treatment may improve quality of life. If and how pediatric dysphagia affects the family is important to know as a clinician. This can lead to how pediatric dysphagia affects quality of life, and give us clues as to how to help families. Future research should focus on predictive factors of how feeding and swallowing disorders impact the family. Examples of predictive factors may include coping behaviors of the family, number of children in the family or nature of the feeding and swallowing disorder.

Coping behaviors of families also could be an important factor when looking at pediatric dysphagia's effect on the family. Research shows that coping behaviors can have an effect on

parenting stress and the impact on the families of children with other disorders such as traumatic brain injury (Friehe, Bloedow, & Hesse, 2003; Stancin, et al., 2008). Family cohesion is another factor indicated in lowering levels of parenting stress (Rodenburg, et al., 2007), and could be a predictor of levels of impact on the family or parenting stress from feeding and swallowing disorders. Treatment approaches on the effects of the IMPACT scale, STRESS scale and FUCNTIONAL scale could be done to help further knowledge base on helping families of children with feeding and swallowing disorders. The knowledge gained from the scales can also be used to determine the most effective therapy.

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