

EATING BEHAVIOR IN CHILDREN WITH
FETAL ALCOHOL SPECTRUM
DISORDERS: A MIXED
METHODS STUDY

By

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Abstract:

Secondary to associated physical defects, global behavioral problems, and co-occurring diagnoses, studies suggest there are problems with nutrition and eating in children with fetal alcohol spectrum disorders (FASDs); however, there is limited research on the effects of prenatal alcohol exposure on childhood eating behavior. A mixed methods approach was used to define the eating behavior in children with FASDs, aged 3 to 5 years, through responses from caregivers of children with FASDs to the Children's Eating Behavior Questionnaire and the Child Behavior Checklist 1.5-5, and through focus groups of healthcare professionals with FASD pediatric experience. There were 74 caregivers and 26 healthcare professionals from across the U.S. and internationally who participated in the study. When compared to a normative sample, the findings from caregiver responses demonstrated atypical eating behavior in preschool-aged children with FASDs characterized by maladaptive appetites, selective eating, slowness in eating, and an excessive need for drinks. In relation to global behavioral problems, it was found that the children with FASDs ate faster if taking a greater number of medications, but slower with somatic symptoms. During stress, caregivers reported the children with FASDs, who exhibited internalizing behaviors, under ate, while those with externalizing behaviors overate. In addition, the children with FASDs, who had both internalizing behaviors and sleep problems, experienced more food fussiness. The healthcare professionals identified atypical eating behavior in the children with FASDs that was influenced by co-occurring diagnoses with or without medications, food hypo- or hypersensitivities, food intolerances, late FASD diagnosis, and nutritional deficiencies. Furthermore, healthcare professionals expressed that the atypical eating behavior in the preschool-aged children with FASDs was impacted by family stress, the limited nutrition knowledge of the children's caregivers, and a need for improved caregiver feeding practices. Findings suggest that the severity of the FASD condition may underlie the children's atypical eating behaviors in association with higher levels of behavioral problems, medications, and stress in the family. With the identification and characterization of atypical eating behavior in preschool-aged children with FASDs, targeted nutrition education and interventions can be developed in an effort to improve nutrition, childhood development, and quality of family life.

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CHAPTER I

INTRODUCTION

The purpose of this mixed methods research was to characterize the eating behavior in children with fetal alcohol spectrum disorders (FASDs) through the perspectives of their caregivers and healthcare providers, since each play an important role in the administration of their nutrition. Phase one of this research analyzed the anonymous responses from caregivers to a cross-sectional internet survey regarding the general and eating behaviors of their children with FASDs, aged 3 to 5 years. The online survey consisted of a socio-demographic questionnaire, a request for children's anthropometric measurements, the Children's Eating Behavior Questionnaire (CEBQ), and the Child Behavior Checklist 1.5-5 (CBCL/1.5-5). The second phase of this study explored the issues that affect the eating behavior in children with FASDs, aged 3 to 5 years, through guided discussions of healthcare providers in focus groups. The discussions provided qualitative data on the eating behaviors encountered during the healthcare professional's delivery of FASD services and care. The findings of this mixed methods research provide formative information, which may contribute to future research efforts in the development of nutrition intervention protocols for atypical eating behaviors in children with FASDs.

Fetal Alcohol Spectrum Disorders

Children from alcohol-exposed pregnancies (AEPs) may present with minimal to severe physical, neurological, and behavioral abnormalities that are lifelong in duration (Wattendorf & Muenke, 2005). The most severe manifestation from maternal alcohol consumption during pregnancy is the diagnosis of fetal alcohol syndrome (FAS), which is also one of the leading preventable causes of intellectual disability in the Western world (Hoyme et al., 2005; Jones, Smith, Ulleland, & Streissguth, 1973; Roebuck, Mattson, & Riley, 1998). Since the severity of alcohol-related impairments vary, the non-diagnostic term, fetal alcohol spectrum disorders (FASDs), has come to represent all of the effects in children from prenatal alcohol exposure (Chudley et al., 2005).

Assessment and Diagnosis of FASD

An awareness of the recognized alcohol-related abnormalities and diagnostic criteria for FASD may aid in the identification of difficulties that could lead to eating and nutrition problems in children with FASDs, aged 3 to 5 years (Wattendorf & Muenke, 2005). The effects related to prenatal alcohol exposure may or may not be evident immediately after birth, even though this is the most advantageous time for a diagnosis (Hoyme et al., 2005). With FASD, an early and accurate diagnosis is important because this will allow for appropriate interventions, such as with nutrition, which may prevent serious secondary outcomes later in life.

There are established diagnostic guidelines in assessing the physical, neurological, and behavioral abnormalities of FASD (U.S. Department of Health and Human Services, 2009). In assessment, FASD may initially be suspect when an infant's

medical records disclose a history of prenatal alcohol exposure or there are symptoms of alcohol withdrawal at birth, such as tremors, seizures, or irritability (Vaux & Rosenkrantz, 2010). The diagnostic screening for FAS would include observations for signs of prenatal and postnatal growth retardation, the characteristic facial dysmorphia, and abnormalities in the central nervous system (CNS).

Surgeon General's Advisory

In response to the identification of adverse fetal outcomes from maternal alcohol consumption during pregnancy, the U.S. Surgeon General issued a warning in 1981 advising pregnant women to refrain from alcohol intake to prevent FASD in children (General, 1981; Warren & Foudin, 2001). To strengthen this alert, a law passed in 1989 required labels to be placed on containers of alcohol that had the same warning message to pregnant women regarding abstinence from alcohol consumption. Years later, the revised 2005 U.S. General's Advisory statement continued to support abstinence of alcohol use in pregnant women, along with adding women preparing or at risk for a pregnancy (U.S. Department of Health and Human Services, 2009).

Prevalence and Cost of FASD

Despite the enactment of legislation, studies report that maternal alcohol consumption and FASD have remained at the same relative rates (Ebrahim et al., 1998; Floyd, O'Connor, Sokol, Bertrand, & Cordero, 2005; May & Gossage, 2001). Similar rates were noted in findings from the 1991 to 2005 Behavioral Risk Factor Surveillance System (BRFSS) survey, which was examined by the Centers for Disease Control and Prevention (CDC) (Denny, Tsai, Floyd, & Green, 2009). Even more recently, a 2010

Australian survey reported women of childbearing age still misinterpret information about alcohol consumption during pregnancy (Peadon et al., 2010).

Upon comparison of epidemiological studies, there have been differences noted in the reported prevalence of FASD, which results in divergent estimations (Chambers, 2007; May et al., 2009). The FASD prevalence estimates may differ secondary to the type of study variables, research method, and sample characteristics used in the investigation. As an example, frequency rates may be given either as per children or live births and have been found to be higher in at-risk individuals, such as for South African (40.5 to 89.2 FASD cases per 1,000 children) or Native American (1.0 to 8.97 FASD cases per 1,000 live births) women (Beckett, 2011; May et al., 2005; Olivier, Urban, Chersich, Temmerman, & Viljoen, 2013).

The primary ways for evaluating the prevalence of FASD have been through active case ascertainment, clinic-based studies, and passive surveillance (May & Gossage, 2001). Definitions of the approaches are as follows: Active case ascertainment locates and examines possible cases within a well-defined, large population; Clinic-based studies obtain data from prenatal clinics within large hospitals; and Passive surveillance systems acquire information through the Birth Defect Monitoring Program. Using prospective studies, Abel and Sokol (1987) calculated the worldwide incidence of FAS at 1.9 cases per 1000 live births and that rates increased to 3.3 cases per 1,000 children as the distinct characteristics of FAS become more apparent with age. From the late 1990s, a literature review of each approach found an overall U.S. rate of 0.5 to 2.0 FAS cases per 1,000 live births and, with the inclusion of FASD cases, the prevalence increased to 9.1 to 10.0 cases per 1,000 live births (May & Gossage, 2001, p. 167). While using a special

variation of active case ascertainment, May et al. noted that, when evaluating a typical U.S. school population of mixed race and socio-economical status, there were 2.00 to 7.00 FAS cases per 1,000 children with a rate of FASD around 2.0 to 5.0% (May et al., 2009, p. 189-190). Similarly, the prevalence of FAS in Oklahoma has been estimated to be approximately 2.0 cases per 1,000 live births, which equates to around 103 infants per year (Burd, 2011).

Due to the contrasting range of FASD prevalence recorded in the various studies, CDC developed the FAS Surveillance Network (FASSNet) ("Fetal alcohol syndrome--Alaska, Arizona, Colorado, and New York, 1995-1997," 2002). One goal of this multi-site program was to standardize FAS identification and diagnosis that, in turn, would promote accuracy and consistency in record keeping. FASSNet analyzed the first 3 years of children's medical records born from 1995 to 1997 in the network's five states of Alaska, Arizona, Colorado, New York, and Wisconsin. The records from FASSNet indicated FAS prevalence was 0.3 to 1.5 cases per 1,000 live births with the higher number of cases originating from the African American and American Indian/Alaskan Native populace. The prevalence and severity of the alcohol-related birth defects contribute to the degree FASD impacts the U.S. healthcare system economy (May et al., 2009; Popova, Stade, Berkmuradov, Lange, & Rehm, 2011). The same disparities in deriving prevalence have influenced the calculation of healthcare cost estimates. The estimated costs of FASD care have increased in the U.S. from \$75 to 321 million in 1984 to \$2.3 to 6.00 billion in 2002 (Lupton, Burd, & Harwood, 2004). Within the annual cost estimates for FASD, the lowest amounts primarily include costs for medical treatment and residential care, while the higher amounts may include additional costs due to loss of

productivity, special education services, semi-support services, and differences in the assumed prevalence rate.

Nutritional Factors

Children with FASDs are at an increased risk for malnutrition and eating problems due to the many abnormalities resulting from either primary and/or secondary alcohol-related disabilities (Nanson, 1992; Nanson & Hiscock, 1990; Uc et al., 1997). Since maternal nutrition can be impacted from excessive alcohol consumption, the children's nutritional problems may begin while in utero, particularly, if the maternal diet was inadequate (Dreosti, 1993a). Following birth, children with FASDs can experience malnutrition and eating problems from alcohol's postnatal consequences of poor suck, iron-deficiency anemia, and gastrointestinal tract abnormalities during infancy (e.g., chronic intestinal pseudo-obstruction) (Carter, Jacobson, Molteno, & Jacobson, 2007; Kvigne, Leonardson, Borzelleca, Neff-Smith, & Welty, 2009; Uc et al., 1997). Equally important, there may be congenital physical abnormalities, such as in micrognathia, dental anomalies, and cleft lip or palate, that occur, which interfere with the mechanics of eating and lead to poor food consumption (Itthagaran, Nair, Epstein, & King, 2007; Sant'Anna & Tosello, 2006). Feeding or eating difficulties also may be associated with the developmental delays, sensory processing disorders, or poor motor control from CNS dysfunction caused by prenatal alcohol exposure (Jirikowic, Kartin, & Olson, 2008; Stromland, 2004). These indications strongly support that children with FASDs have atypical eating behaviors not yet fully recognized.

Purpose Statement

Certainly, appropriate eating behaviors are vital in all children for proper nutrition for growth and development but are of particular importance in children with disabilities (Kerwin, 1999). Secondary to the complex, integrated physiological responses required for feeding, any deficit in structure and/or function, such as seen with FASD, could lead to difficulties in performing eating activities. If atypical eating behaviors are present and persistent, this could lead to nutritional deficiencies and exacerbate the growth and developmental issues already documented with FASD.

Various anecdotal FASD guidelines for caregivers and healthcare providers list age-specific eating strategies as important in the care and clinical management of feeding difficulties seen in children with FASDs (NOFAS, 2012; “Strategies for Children (3-12) with an Fetal Alcohol Spectrum Disorders,” 2011). By association, children with FASDs may have inadequate food intake and malnutrition from co-occurring conditions, diagnosed as intellectual disabilities, sensory processing disorders, abnormal intestinal function, and dyspraxia (Franssen, Maaskant, & van Schrojenstein Lantman-de Valk, 2011; Itthagarun, Nair, Epstein, & King, 2007; Nanson, 1992; Uc et al., 1997; Van Dyke, Mackay, & Ziaylek, 1982). Although a relationship between maternal-fetal nutrition and FASD is an area of current research, research on the nutrition and eating behavior in children with FASDs, ages 3 to 5 years, has yet to be fully described (Kvigne et al., 2009; Werts, Van Calcar, Wargowski, & Smith, 2014; Wozniak et al., 2013). In view of this, it appears nutrition problems in children with FASDs are present, but there is a little evidence-based literature specifically addressing the eating behavior in children with FASDs.

Since caregivers and healthcare providers of children with FASDs play important roles in pediatric nutrition care management, the goal of this research focused on advancing the understanding of how eating behavior is manifested in children with FASDs from their perspectives. Using survey and focus group methodologies for data collection, an in-depth understanding of the eating behavior in the children was developed through quantitative and qualitative analysis. Since eating behavior is difficult to measure using one specific measure alone, a mixed methodology effectively explored and explained this broad and varied phenomenon in children with FASDs. The intention of the study was to broaden knowledge regarding eating behavior in children with FASDs in an effort to provide formative knowledge for the future development of targeted and effective nutrition clinical protocols that may improve the children's compromised growth, development, and functioning secondary to prenatal alcohol exposure.

Research Questions and Hypotheses

Research Question 1. What are the types of eating behavior in children with FASDs as reported by their caregivers?

The *hypothesis* was that caregivers would report atypical eating behavior in children with FASDs, aged 3 to 5 years, as assessed online by socio-demographic characteristics, children's anthropometric measurements, and the Children's Eating Behavior Questionnaire (CEBQ) (Wardle, Guthrie, Sanderson, & Rapoport, 2001).

Research Question 2. Are the atypical eating behaviors in the children with FASDs, aged 3 to 5 years, associated with childhood global behavioral problems?

The *hypothesis* was that caregivers would report atypical eating behavior in children with FASDs as assessed online by the CEBQ (Wardle et al., 2001), which will be positively associated with higher levels of behavioral problems as reported online by the Child Behavior Checklist 1.5-5 (CBCL/1.5 – 5) (Achenbach & Rescorla, 2000).

Research Question 3. How are eating behaviors manifested in children with FASDs, aged 3 to 5 years, as discussed in focus groups of healthcare providers, who are involved in FASD care and services?

The *hypothesis* was that healthcare providers in focus group discussions would report encountering children with FASDs who have atypical eating behaviors that affect their health or development.

Summary

Due to the physical, neurological, and behavioral deficits from prenatal alcohol exposure, children with FASDs experience a diminished quality of life compared to children with typical development (Wattendorf & Muenke, 2005; Wilton & Plane, 2006). Consequently, the adverse outcomes from FASD impair everyday life skills and functions necessary for use in cognition, learning, language, memory, and adaptation behavior (Jirikowic et al., 2008; Mattson & Riley, 1998). If there are atypical eating behaviors present, this could negatively influence the children's nutrition and already compromised physical, mental, and health status. Caregivers and healthcare providers administer management of the children's nutrition and feeding and can be instrumental in describing any observed atypical eating behaviors. With the characterization of atypical eating behavior, as defined by the caregivers and healthcare providers, specific nutrition clinical

protocols may be developed to improve nutritional status and potentially reduce condition severity in children with FASDs.

CHAPTER II

REVIEW OF LITERATURE

Introduction

This review discusses relevant literature describing the alcohol-related birth defects children with FASDs, aged 3 to 5 years, have that can cause difficulty with food consumption and nutrition. Since a child needs to eat properly to grow, learn, and interact socially with others, it is important to define the abnormalities occurring from prenatal alcohol exposure that place children at higher risk for atypical eating behaviors and malnutrition. To have a better understanding of the factors surrounding fetal alcohol exposure and its effects on eating behavior, this synopsis also includes brief summaries of alcohol metabolism, the history of FAS, maternal characteristics associated with prenatal alcohol exposure, and childhood behavioral assessment instruments. During the search of existing literature, the review revealed only a few studies that specifically examined behaviors related to eating behavior or nutrition in children with FASDs, aged 3 to 5 years; thereby, demonstrating the importance in conducting further nutrition research in this area.

Alcohol

Chemically, alcohol is a volatile organic molecule consisting of a saturated carbon chain that has a hydroxyl group attached to one of the carbon atoms, instead of a hydrogen ion (Fadda & Rossetti, 1998). Ethanol, the type of alcohol in distilled beverages, is one of the finished products of fruits, vegetables, and grains (sugars) after fermentation with yeast. Even though alcohol has seven kilocalories per gram, it is a substance said to contain empty calories because it has only negligible protein, vitamin, or mineral content (Anonymous, 1928; Lieber, 1980). Since alcohol has no meaningful physiologic value, there is not a designated normal blood level in the human body.

Upon consumption, alcohol is readily absorbed throughout the entire gastrointestinal tract, including the esophageal and gastric linings, and interferes with both gastrointestinal structure and function (Bode & Bode, 1997). When in contact with the gastrointestinal tract, it causes inflammation of the mucosa, along with impaired motility of gastric and small intestinal muscle. Consequently, absorption of food and nutrients is decreased because of the damage to the absorptive surface and an alteration in transit time. After absorption, the transport, storage, and excretion of nutrients also undergo alterations due to the effects of alcohol metabolism in the human body.

The amount of alcohol absorbed in the blood or the blood alcohol concentration (BAC) is measured in milligrams (mg) per deciliter (dL) or grams percent (g %) and is an indicator of the degree of intoxication (Zakhari, 2006). The BAC will vary depending on the beverage type, the quantity consumed, the presence of genetic variations in the alcohol metabolic enzymes, and the individual gastric emptying rate. It has been determined that there are increasing levels of impairment and deleterious effect on body

cells with higher BACs, notably as the BAC rises above 50 mg/dL or 0.05 % (Zakhari, 2006, p.245).

Since it is a small, lipid-soluble molecule, alcohol passes unchanged into the circulatory system from the gastrointestinal tract and enters cells through passive diffusion (Zakhari, 2006). In an attempt to eliminate injury once in circulation, alcohol is detoxified mainly in the liver through the oxidative pathways of metabolism (Lieber, 1980). Interestingly, alcohol metabolism follows pathways common to the catabolism of fatty acids, even though its chemical structure has a likeness to that of carbohydrates. During metabolism within the hepatocytes, alcohol is first converted to acetaldehyde by the alcohol dehydrogenase enzyme (ADH) and, then, to acetate by aldehyde dehydrogenase (ALDH). Ultimately, there is conversion of the alcohol molecule to carbon dioxide and water, along with the release of other compounds, such as NADH. Nonetheless, a small amount of the alcohol in the body remains unmetabolized and its excretion is through either the breath or the urinary tract system (Das Kumar & Vasudevan, 2008; Zakhari, 2006).

While it is necessary for the human body to undergo detoxification, the process of alcohol metabolism itself affects almost all other major metabolic processes and pathways, triggering additional adverse events (Zakhari, 2006). The catabolism of alcohol results in excessive acetaldehyde production, an elevated NADH:NAD⁺ ratio, metabolic competition, and induced metabolic tolerance, which are all factors that can disrupt the body's normal metabolic pathways. The degree of interference depends on the quantity of alcohol consumed and the levels of the vitamins, minerals, cofactors, and metabolites involved in homeostasis (Lieber, 1980). Disruption of normal metabolic

processes from alcohol may lead to hyperuricemia, hyperlipidemia, hyperlacticacidemia, and ketonemia. Other consequences from the consumption and metabolism of alcohol are the formation of harmful adducts, production of reactive oxygen species (ROS), hypoxia in hepatocytes, and, if women are pregnant, abnormalities in fetal development (Jones et al., 1973; Zakhari, 2006).

Since the 1900s, researchers have sought to understand the effects of prenatal alcohol exposure responsible for the abnormalities sustained during fetal development (Jones et al., 1973; Lemoine, Harousseau, Borteyru, & Menuet, 2003). Biochemical experimentation has shown that, after maternal consumption, alcohol directly crosses over into the developing fetus via the placenta by diffusion (Wattendorf & Muenke, 2005). The influence of alcohol on placental anatomy and function is an area of interest since maternal transport of nutrients to the fetus is vital for appropriate fetal growth and development (Gundogan et al., 2008). It has been demonstrated in animal studies that alcohol reduced the level of insulin-like growth factor (IGF) signaling molecules; thereby, inhibiting maturation of uterine vasculature and causing malformation and dysfunction of the placenta. With compromised placental function, there is impairment in the delivery of nutrients with an increased risk of nutritional deficiencies, anomalies in organogenesis, and growth retardation in the fetus (Breedon, 2009; Gundogan et al., 2008).

When alcohol passes from the placenta into the fetal blood stream, the fetus receives a dose approximately equivalent to the maternal BAC due to alcohol's rapid placental transfer, low molecular weight, and solubility in both water and fat (Burd, Blair, & Dropps, 2012). However, even after the maternal blood level has returned to normal,

the fetal BAC remains at an elevated level for at least another 3 to 4 days. This sustained fetal blood concentration is primarily because of the fetal liver's limited metabolic capacity to effectively metabolize alcohol and the residual amount that remains in the amniotic fluid surrounding the fetus (Anderson & Anderson, 1986). Building upon the understanding that the fetus receives exposure to alcohol directly from maternal consumption, a consideration of the history of FASD and the maternal predisposition factors to alcohol intake will provide more details regarding the development of FASD.

History of FASD

As interpreted by some historians, there are records dating back to the ancient times that document an earlier awareness of the detrimental interaction between alcohol and fetal development (Calhoun & Warren, 2007). One presupposition given believes the ancient Greek and Roman philosophers discouraged alcoholic beverages on the wedding night because the harmful effects of alcohol on the fetus occurred at the time of conception. Additional support presented was from select Biblical scriptures, such as in the *Book of Judges*,

Behold now, thou art barren, and bearest not: but thou shalt conceive, and bear a son. Now therefore beware, I pray thee, and drink not wine nor strong drink, and eat not any unclean thing. (Judges. 13: 3-4 KJV)

and in Aristotle's passage, "*Foolish, drunken, and harebrained women most often bring forth children like unto themselves, morose and languid*" (Burton, 1906, p. 82).

However, an opposing interpretation of the ancient literature posited that the Greek and Roman philosophers' concerns were actually related to alcohol's effect on

reducing the body temperature of the male partner to increase the chance of having a female infant (Abel, 1999). The proclivity during this ancient era was that a female infant was a deformity, making a male, the preferred infant gender. Ernest L. Abel (1999) advocated this view in his paper, “*Was the Fetal Alcohol Syndrome recognized by the Greeks and Romans?*” and reported there was no evidence supporting the supposition of ancient philosophers having an awareness of fetal alcohol syndrome. He also found this lack of understanding was upheld after his review of scriptures and Far East writings (Abel, 1997).

From media and medical reports in the 1700s, there was mention of an increase in birth defects and infant mortality during England’s ‘gin epidemic’ (Calhoun & Warren, 2007). The reason proposed for these poor fetal outcomes was that the lower price of gin prompted more alcohol consumption in women of childbearing age. In the 1751 etching, *Gin Lane*, William Hogarth illustrated the deplorable conditions intoxicated women lived in with their young children during the gin epidemic (Abel, 2001). Over the years, this depiction has come to represent an association of maternal alcohol consumption and FASD. Yet, Abel’s review of the scene disputed that Hogarth had any understanding of fetal alcohol syndrome. Whether or not these earlier historical excerpts reflect a true understanding of the association between maternal alcohol consumption during pregnancy and harm to the fetus is debatable.

The earliest known assessment of children with documented exposure to alcohol prenatally was in 1899 (Sullivan, 2011; initially published in the *Journal of Mental Science* and recently reprinted in the *International Journal of Epidemiology*). Dr. W. C. Sullivan, a Liverpool physician, was the first to report on the problems in children of

incarcerated alcoholic mothers. He concluded from his work that maternal alcohol consumption was not conducive to normal fetal growth and development. Since this early study, research has continued investigating prenatal alcohol exposure and the effects seen in children with FASDs (Jones & Smith, 1973).

In 1968, Paul Lemoine and colleagues published the first article in medical literature on the effects seen in children from prenatal alcohol exposure (Lemoine et al., 2003). Nevertheless, owing to the article's printing in a little-known French journal, this pioneering research did not receive much attention until, approximately 5 years later in the U.S, similar research was conducted by Jones and fellow researchers (Jones & Smith, 1973; Koren & Navioz, 2003). A cohort study by Jones et al. in 1973 on eight children, whose mothers were alcoholics, found a strong association between chronic maternal alcoholism and a specific pattern of morphogenesis in the exposed children.

The disorder observed by Jones et al. received the name, fetal alcohol syndrome (FAS), which has come to represent the specific pattern of abnormalities in children who had exposure to alcohol during fetal development (Jones et al., 1973). Over time, alcohol's effect on the fetus was found to vary from the defined archetype of FAS (Kvigne et al., 2004; Mattson, Riley, Gramling, Delis, & Jones, 1998). Hence, the nomenclature, as designated by a committee of the Institute of Medicine (IOM), expanded to include the following terms: Alcohol-related birth defects (ARBDS, birth defects from prenatal alcohol exposure), alcohol-related neuro-developmental disorder (ARND, disorders with functional and mental impairment), and partial fetal alcohol syndrome (pFAS, partial facial dysmorphology) (Kodituwakku, 2007; May & Gossage,

2011; Xu, Tang, & Li, 2008). FASD is the non-diagnostic blanket term for all of these diagnoses and is used in this paper (Bertrand et al., 2004).

Maternal Alcohol Consumption

Considering alcohol use and risks, women, in general, may drink less alcohol per setting than men but are more likely to have adverse consequences from alcohol consumption (Brienza & Stein, 2002; Tuchman, 2010; van Beek, de Moor, Geels, Willemsen, & Boomsma, 2014). One reason for this difference is due to the physiological variances in the absorption and metabolism of alcohol between women and men, which results in women experiencing higher BACs at similar intakes (Health, 1999). Additional gender traits that make women more prone to alcohol's toxicity include women's lower percentage of total body water, greater body fat percentage, and reduced activity of the gastric ADH enzyme.

Metabolism also varies amongst individual women based on the presence of genetic polymorphisms, such as in ADH (May & Gossage, 2011). Genetic polymorphisms in ADH, an enzyme responsible for the conversion of alcohol to aldehydes and ketones, would influence the level of expression and function. It has been reported that, in women that have children with FAS, there appears to be lower levels of the protective ADH variants.

A strong predictor of maternal alcohol use during pregnancy is the level of alcohol consumption prior to pregnancy, which is also a time of concern (Floyd, Decoufle, & Hungerford, 1999). It is not only pregnant women but all women of childbearing age who are at risk for bearing a child with FASD (Ebrahim et al., 1998).

The risk of FASD for non-pregnant women of childbearing age is because, without proper birth control, there is the chance of alcohol exposure in an unplanned pregnancy. Often, the confirmation of an unplanned pregnancy does not take place until several weeks into the first trimester, which increases the potential for fetal alcohol exposure in the early stages of gestation.

The CDC advises screening all women, who are pregnant or of childbearing age, for their alcohol intake and to counsel them about the harmful effects to the fetus from alcohol consumption during pregnancy (Chudley et al., 2005; U.S. Department of Health and Human Services, 2009). Two instruments that may be used in screening for intake of alcohol are the T-ACE (tolerance, annoyed, cut down, and eye opener) and TWEAK (tolerance, worry, eye opener, amnesia, and cut down). After screening, if there is a positive history of alcohol intake and the woman is pregnant, the recommendation is to provide a brief alcohol intervention or a referral to a substance abuse counselor (Chang et al., 2005). With early screening and identification of maternal alcohol consumption pattern, women at high risk may receive treatment and counseling regarding the use of alcohol during pregnancy in order to prevent FASD (Sharpe et al., 2004).

Maternal alcohol consumption pattern

To differentiate the level of drinking that may put a woman at risk for having a child with FASD, patterns of alcohol intake and number of drinks per setting have been evaluated (Barr & Streissguth, 2001). Two categories of drinking patterns in women who had children with FASDs were binge drinking, which is having more than three standard drinks at one time, and frequent drinking, defined as more than 24 standard drinks per

month but less than three at a time (May & Gossage, 2011; NIAAA, 2004). A standard drink is any distilled beverage containing 14 grams of alcohol, which is analogous to 5 fl. oz. of wine, 12 fl. oz. of beer, 4 fl. oz. of liqueur, or 1½ fl. oz. of whiskey (Alcoholism, 2005). Of the two categories, binge drinking causes the most injury to the fetus because it results in a higher peak maternal BAC per setting (May & Gossage, 2011). With frequent drinking, there is an increased risk for FASD because there is an episodic presence of alcohol throughout fetal development. A study compared the two levels of maternal alcohol intake in 1,439 women to the rates of FASD in the offspring, aged birth to seven years. The study found 38% of the women with binge drinking and 8.1 % with frequent drinking experienced a singleton birth with FASD (Barr & Streissguth, 2001, p. 285).

National maternal alcohol consumption rates

Determining the risk of FASD includes appraisal of the extent of alcohol consumption in women (U.S. Department of Health and Human Services, 2009). To examine the number of pregnant and non-pregnant women, aged 18 to 44 years, who were positive for any alcohol use or binge drinking, the CDC analyzed BRFSS data from 1991 to 2005 (Denny et al., 2009). In the BFRSS survey, assessment was limited to alcohol consumption within the last 30 days, with the term, any alcohol use, representing women who consumed at least one alcoholic beverage, and binge drinking, as having five or more alcoholic beverages at one setting. Analysis of the BFRSS survey responses revealed 12% of 22,027 pregnant respondents were positive for any alcohol use and, within this group, 1.9% participated in binge drinking. In women of childbearing age, 53.7% reported any alcohol use and 12.2% for binge drinking (Denny et al., 2009, p.4).

Characteristics of pregnant women consuming alcohol: Analysis of the 2001 to 2005 BRFSS data on 13,820 pregnant women, aged 18 to 44 years, revealed characteristics of pregnant women who consumed any alcohol as the following: 17.7% were between the ages of 35 to 44 years, 11.2 % had attended college, 14.4% were college graduates, 13.7% had employment, and 13.4% were single (Denny et al., 2009, p. 5). It was also observed that binge drinking in pregnant women was more prevalent in those employed (2.3%) or unmarried (3.6%) than in those unemployed (1.3%) or married (1.1%). The reason for these observed characteristics has not yet been determined. However, possible inferences presented were as follow: Older women may already have problems with alcohol abuse and continue to drink when pregnant; Women, who are educated and/or employed, may have extra income to purchase alcohol; and Unmarried women may attend more social events with access to alcoholic beverages (Denny et al., 2009).

The characteristics of pregnant women reported drinking alcohol in the BRFSS 2001 to 2005 database have not changed drastically over the years when compared to previous BRFSS and other national surveys (Ahluwalia, Mack, & Mokdad, 2005; Serdula, Williamson, Kendrick, Anda, & Byers, 1991). When reviewing the BRFSS data from 1985 through 1988, the survey of the 21 participating states found that 25% of the 1712 pregnant women, aged 18 to 45 years, consumed alcohol (median of four drinks per month) (Serdula et al., 1991, p. 877). In addition, of those pregnant women who consumed alcohol, many were not married (28%). In like manner to the 2001 to 2005 BRFSS results, the 1988 National Maternal and Infant Health Survey had reported that

pregnant women who consumed alcohol were more prevalent in the age group of 35 years and older (Anonymous, 1995).

Characteristics of women and prevalence of FASD: Population-based Studies.

Nevertheless, there appears to be a difference in the maternal characteristics associated with giving birth to a child with FASD in comparison to the BFRSS or other national survey data representing combined population-based studies of various countries, such as the U.S., Italy, and South Africa (May & Gossage, 2011). From the population-based studies, women of lower socioeconomic status with little education had the highest prevalence of FAS and pFAS. Other associated characteristics were poor living conditions and being undernourished, which were factors thought to be additive to the risk of FASD.

In an epidemiological review, May and Gossage identified maternal risks associated with giving birth to an infant with FASD (May & Gossage, 2011). Cofactors of risk were women over the age of 25 years, who have had a greater number of previous pregnancies and at least three or more living children. Over time, this suggests the more pregnancies and children that a woman has, who is consuming alcohol during a pregnancy, the more chances there are for the offspring to have alcohol-related impairments.

Besides economic status, age, parity, and gravidity, the maternal traits related to body profile, emotional state, and social relations were noted to have an association with risk for FASD (May & Gossage, 2011). Research has shown that, in general, women, who have children with FASDs, have a smaller stature. It follows that, when the pregnant

woman of smaller size drinks alcohol, there is propensity for a higher BAC, which increases risk for FASD. Along with body size, maternal health status is important since chronic alcohol consumption, particularly if the drinking started at a young age, may compromise maternal nutrition and, subsequently, fetal health. Other characteristics reported that might increase the risk of having children with FASDs are the following: Maternal depression, a child taken by social services, domestic violence, substance abuse of other drugs, and other family members with substance abuse problems.

When evaluating the epidemiologic surveys and reviews, there are design elements to consider. The BRFSS assessed U.S. data on the number of pregnant and non-pregnant women consuming alcohol without relating to FASD prevalence (Ahluwalia et al., 2005). The systematic review by May and Gossage represented population-based data on the association of maternal risk factors and FASD prevalence from various countries (May et al., 2011). The survey data provided by each differ in assessment approach.

Maternal nutritional status and FASD

Maternal nutritional status is important both prior to and during the pregnancy, especially in the context of alcohol use (Kaiser & Allen, 2002). It is well known that maternal dietary behaviors affect prenatal outcomes, whether there is alcohol consumption or not (Shankar, Ronis, & Badger, 2007; Vause, Martz, Richard, & Gramlich, 2006). Pregnancy, by itself, changes the requirements of nutrients and alters detoxification of drugs, such as with alcohol (King, 2000). There is evidence supporting that excessive alcohol intake negatively affects maternal diet, and, even more importantly, maternal malnutrition exacerbates the effects of alcohol on prenatal

outcomes (Shankar et al., 2007). As was seen in an animal model, a malnourished pregnant rat, when compared to a well-nourished pregnant rat, had poorer metabolism and clearance rate of alcohol. With impaired metabolism and clearance rate of alcohol from maternal malnutrition, the result would be a higher alcohol concentration in the fetus (Shankar et al., 2007).

To evaluate the relationship between maternal nutrition and FASD risk, researchers investigated mothers of children with FASDs in South Africa, Russia, and the Ukraine to determine the influence of nutrient deficiencies as cofactors (May & Gossage, 2011). In South Africa, mothers of children with severe FASDs had diets with reduced amounts of riboflavin, calcium, and docosapentaenoic acid (DPA) when compared to controls (May et al., 2004). Results from a study on women consuming alcohol, who lived in Russia and the Ukraine, found low serum levels in zinc and/or copper (Keen et al., 2010). The findings imply that specific nutritional deficiencies may increase the risk of FASD, beyond that of a poor diet alone.

In sum, with alcohol intake in pregnant women, nutrients may become insufficient or deficient due to changes in dietary intake and/or alterations in normal metabolic processes (Shankar et al., 2007). Maternal health may be detrimentally affected by alcohol from changes in protein metabolism, blood glucose regulation, and micronutrient levels of thiamine, vitamin A, the B vitamins, vitamin D, magnesium, and zinc (Dreosti, 1993b; Vaux & Rosenkrantz, 2010). Alcohol also disrupts the normal maternal-fetal unit, causing a decrease in the delivery of essential nutrients to the fetus necessary for growth and development. The combined effect of maternal nutritional

imbalances and alcohol consumption appears to influence the genetic expression of FAS and poor birth outcomes.

Effects of Prenatal Alcohol Exposure

The alcohol-related effects on the fetus from maternal alcohol consumption are multi-dimensional and adversely affect the structure and function of all embryonic cells, particularly, in the liver, skeleton, and brain (Shankar et al., 2007). Cellular damage may occur from increased oxidative stress secondary to the production of excessive free radicals during the metabolism of alcohol. With an imbalance between antioxidant defenses and free radicals, there is loss of cellular integrity, leading to lipid peroxidation, abnormal cellular differentiation, and disrupted cellular migration (Denkins et al., 2000). The compromised cellular state also gives rise to mitochondrial impermeability, decreased cell adhesion, malformed glial cells, and defective neurotransmitters (Goodlett & Horn, 2001). Severity of cellular injury to the fetus from alcohol exposure is relative to the dose, pattern, and time of the exposure during the gestational period (Goodlett & Horn, 2001; May & Gossage, 2011). Consequently, during critical periods in fetal development, the greater the amount and frequency of alcohol consumed by the pregnant woman, the more alcohol severely damages fetal tissues. Considering the diversity of alcohol-related effects, it appears there is not a single factor but a multitude of mechanisms, directly or indirectly, that may be involved with the phenotype of FASD.

Children with FASDs, aged 3 to 5 years

By aged 3 to 5 years, children with FASDs will likely be exhibiting problems that prompt their parents or caregivers to seek professional counseling and intervention

(Caley, Winkelman, & Mariano, 2009; U.S. Department of Health and Human Services, 2009). The adverse outcomes in children from prenatal alcohol exposure become more apparent with age, as evidenced by deficits in age-appropriate growth, physical anomalies, and CNS abnormalities that aid in confirmation of the FASD diagnosis during the preschool years (U.S. Department of Health and Human Services, 2009). Since head circumference is an accurate measurement in young children, the physical sign of microcephaly, especially, along with the characteristic facial features, may lead to a diagnosis of FAS or FASD (Astley, 2010). However, due to the broad range of abnormalities, FASDs are more commonly diagnosed at a later stage during childhood when the higher levels of CNS functioning can be tested. The Washington State FAS Diagnostic and Prevention Network (FAS DPN) have reported the mean age for an FASD diagnosis was around 9 years old (Olson, Jirikowic, Kartin, & Astley, 2007).

Growth in Children with FASDs, aged 3 to 5 years

As part of the FAS or FASD diagnosis, the criteria for growth deficiency requires one of the following: A low birth weight for gestational age, a decline in weight over time that is not due to malnutrition, and a weight that is lower than normally expected for height (U.S. Department of Health and Human Services, 2009). Studies report that, secondary to intrauterine growth retardation, children with FAS are small for gestational age at birth and have growth deficiencies that persist throughout their lifespan (Jones et al., 1973; Kvigne et al., 2004; U.S. Department of Health and Human Services, 2009). Like FAS, FASD may have growth deficits but there are also indications of obesity (Spohr & Steinhausen, 1984; Truong, Reifsnider, Mayorga, & Spitler, 2013; Werts et al., 2014).

Physical Anomalies in Children with FASDs, aged 3 to 5 years

There are various descriptions of congenital physical anomalies in children with FASDs (Church & Kaltenbach, 1997; U.S. Department of Health and Human Services, 2009). The anomalies may exist in the child's outward appearance and/or as a disruption of organ structure and function. Significant anatomical birth defects include malformations of the brain and, for an FAS diagnosis, the facial characteristics of a smooth philtrum, thin vermilion, and small palpebral fissures (Burd & Martsolf, 1989; Stratton, Howe, & Battaglia, 1996). In the major organ systems, there has been identification of cardiac, renal, pulmonary, skeletal, and craniofacial abnormalities in children with FASDs (Burd & Martsolf, 1989; Stratton et al., 1996). The organ abnormalities include the following: Cardiac (e.g., aberrant great vessels, Tetralogy of Fallot, functional murmurs, and septal defects), renal (e.g., renal failure, horseshoe kidneys, aplastic/dysplastic/hypoplastic kidneys, hydronephrosis, and ureteral duplications), pulmonary (e.g., upper airway obstruction or respiratory distress syndrome), skeletal (e.g., Klippel-Feil syndrome, flexion contractures, congenital hip dislocation, scoliosis, shortened fingers with fusion of bones in hands and arms, and radioulnar synostosis), and craniofacial (e.g., maxillary hypoplasia, micrognathia, retrognathia, dental malocclusions, absent or malrotated dentition, and cleft lip/palate).

Congenital abnormalities of the sensory organs have also been documented in children with FASDs (U.S. Department of Health and Human Services, 2009). During fetal development, the ocular, auditory, and craniofacial systems form from the ectoderm layer so each may be affected simultaneously from an alcohol-related insult (Church & Kaltenbach, 1997). Ocular abnormalities may consist of strabismus, corneal defects,

myopia or hyperopia, and malformed retinal vessels, while auditory problems may include poorly formed auricles, auditory canal stenosis, and hearing loss (Church & Abel, 1998; Stromland & Pinazo-Duran, 2002). Other alcohol-related consequences in the children may present in the nasal cavity as a small nose or a flattened nasal bridge (Church & Kaltenbach, 1997).

CNS Abnormalities in Children with FASDs, aged 3 to 5 years

The area of the brain affected from prenatal alcohol exposure influences the type and degree of neurological deficits and maladaptive behaviors seen in the children with FASDs, aged 3 to 5 years (Burd & Martsolf, 1989). The primary and secondary problems in CNS function become more discernible during progression through childhood. Primary disabilities, which occur from the direct effects of prenatal alcohol exposure, would relate to deficits in cognition, learning, hearing, and motor skills (Franklin, Deitz, Jirikowic, & Astley, 2008; Rasmussen, Andrew, Zwaigenbaum, & Tough, 2008). Secondary disabilities, which occur after birth as a result of the primary disabilities, refer to problems in adaptive behavior, communication, and daily living skills. Since the CNS continues to develop throughout the entire gestational period, there is a greater susceptibility for the child to have neurological disabilities from prenatal alcohol exposure (Vaux & Rosenkrantz, 2010).

One of the following CNS abnormalities must be present for the diagnosis of FAS or FASD in the children: A decreased head circumference or CNS structural anomaly at birth (e.g., microcephaly, corpus callosum agenesis, and hypoplasia of the cerebellum), neurological problems (e.g., poor balance, hearing loss, and impaired motor tone/skills

without any other etiology), and functional problems (e.g., deficits/delays in cognition, executive function, motor functioning, attention span/hyperactivity, and/or social skills) (Bertrand et al., 2004; U.S. Department of Health and Human Services, 2009). The FASD diagnostic criteria allow for variation since the CNS may be affected differently in each child that has had fetal alcohol exposure. The CNS injury in children with FASDs may manifest as seizures, mental health disorders regulatory dysfunction, and adaptive problems (Bell et al., 2010; Mattson & Riley, 1998; Mattson, Riley, Gramling, Delis, & Jones, 1997; Nicita et al., 2014; Rasmussen et al., 2008).

Mental health disorders, such as autism spectrum disorders (ASD), reactive attachment disorder, and attention-deficit/hyperactivity disorder, are co-occurring diagnoses in children with FASDs (Burd, Carlson, & Kerbeshian, 2007; Prevention, 2007). From caregiver reports on 400 or more subjects with prenatal alcohol exposure, it was found that 94% of the children had a history of mental problems (A.P. Streissguth, Barr, Kogan, & Bookstein, 1996). In the Diagnostic and Statistical Manual, fifth edition, FASD is not listed separately but in the appendix, under the category of Neurodevelopmental Disorder-Prenatal Alcohol Exposure (ND-PAE), as a disorder requiring follow-up (Association, 2013). ND-PAE is an example given in the category, Other Specified Neurodevelopmental Disorder.

Due to CNS damage, young children with FASDs exhibit neurobehavioral deficits in adaptive, social, and sensory regulatory functions (Carr, Agnihotri, & Keightley, 2010; Franklin et al., 2008). The deficits affect skill development in daily living activities, self-care, social interaction, and communication (Jirikowic et al., 2008). Using the Short Sensory Profile and the Child Behavior Checklist, evaluation of 44 children, aged 5 to 10

years, suggested children with FASDs may not adapt well to their environment secondary to difficulty with sensory processing (Franklin et al., 2008). The authors noted that the damage to the brain from alcohol results in the inability of the child to regulate and filter sensory stimuli on a regular basis.

Related to CNS regulatory dysfunction, children with FASDs frequently have persistent sleep disturbances with reports of delay in sleep onset, insomnia, night awakenings, and sleep disordered breathing (Chen, Olson, Picciano, Starr, & Owens, 2012; Jan et al., 2010). Wengel et al. reported that children with FASDs, aged 3 to 6 years, had more difficulty with sleep when compared to children with typical development, particularly in regards to sleep onset latency (Wengel, Hanlon-Dearman, & Fjeldsted, 2011). Difficulties with sleep in individuals with typical development have been found to have an association with additional health and behavior problems, such as diabetes, weight gain and obesity (Knutson, Spiegel, Penev, & Van Cauter, 2007).

Nutritional Problems in Children with FASDs, aged 3 to 5 years

Whether a child has had prenatal alcohol exposure or not, many parents/caregivers express concern over their preschool child's feeding behavior, since this is a period of important developmental transition in which the child is becoming an independent eater (Samour & Helm, 2005). It is at this age children begin participating in a greater number of meal time activities, such as sitting in a chair, serving themselves food, passing food to others, and holding conversation at the table (Story, Holt, & Sofka, 2002). Self-feeding progresses with the preschooler learning to place food in the mouth

by using a fork or scooping food onto utensils with fingers and to consume liquids from an age-appropriate cup.

The feeding difficulties seen in most young children with typical development are short-lived and self-limiting, while atypical eating behaviors persist in children with physical, behavioral, and developmental abnormalities (Liu, Stein, & Faith, 2013). Children with FASDs have physical, neurological, and behavioral problems that interfere with their feeding and are a nutritional concern for their caregivers and healthcare providers. Yet, there is only a small number of studies that have sought to identify problems with eating and nutrition in young children with FASDs (Fuglestad et al., 2014; Fuglestad et al., 2013; Werts et al., 2014; Wozniak et al., 2013).

Nutrition and eating problems related to poor motor, sensory processing disorders, and maladaptive behaviors may exist throughout childhood, affecting the children's growth and development (Nadon, Feldman, Dunn, & Gisel, 2011). During infancy, feeding problems, such as a poor suck and nursing difficulties, have been recorded in the children, along with many having a past medical history of hospital diagnoses for failure to thrive (Kvigne et al., 2009; U.S. Department of Health and Human Services, 2009). The infants with prenatal alcohol exposure may also require enteral feedings until there is achievement of adequate oral intake.

Nutrition issues, involving weight, have been documented in children with FAS or FASD (Fuglestad et al., 2013; Werts et al., 2014). Growth retardation in children with FAS is present at birth and reported to continue throughout the preschool years without compensatory or catch-up growth (Jones et al., 1973; Kyllerman et al., 1985; A. P.

Streissguth, Clarren, & Jones, 1985). Similarly, children with FASDs have records of growth deficiency and underweight; however, in a recent study on children with FASDs, aged 2 to 19 years, the FASD group had a higher prevalence of overweight and obesity compared to the underweight FAS group (Fuglestad et al., 2014). The effect of prenatal alcohol exposure regarding excess weight in FASD is thought to be from dysfunction of the metabolic and endocrine systems.

Alcohol-related abnormalities in motor and sensory processing can impact nutrition and eating in children with FASDs (Kalberg et al., 2006; Wengel et al., 2011). Proper oral and fine motor control and sensory regulation are necessary for preschool children who are learning to consume new foods and beverages (Bruns & Thompson, 2010). Gross and fine motor skills, used in handling utensils or in the mechanics of eating, may be affected and limit adequate dietary intake in children with FASDs (Doney et al., 2014). There is documentation that children with prenatal alcohol exposure have sensory processing disorders, which are known to cause atypical sensations, such as a hypo- or hypersensitivity to tactile, taste/smell, or auditory stimuli (Carr et al., 2010; Dunn, 1997; Franklin et al., 2008). Because of an abnormal sensory sensitivity, there may be selective eating or aversions to particular food tastes, smells, or textures that could lead to a lack of variety in the diet and poor nutrition (Farrow & Coulthard, 2012).

CNS impairment from prenatal alcohol alters behaviors and skill development in children (U.S. Department of Health and Human Services, 2009). Age-appropriate skills are required for successful family mealtimes, daily living activities, and independent self-feeding for the all children, aged 3 to 5 years (Mogharreban & Nahikian-Nelms, 1996). Jirikowic et al. (2008) described the adaptive, social, and behavioral functions in 25

children with FASDs, aged 5 to 8 years, in comparison to 23 children with normal development. Using the Scales of Independent Behavior-Revised, caregivers reported the levels of the children's neurobehavioral function with the personal-living and basic skills subscales that included behavioral functions, such as cleaning off the table after a meal, the preparation of simple snacks, and taking appropriate portions of food. Significant differences were found in eating and meal preparation between the children with FASDs and the control children.

Recently, in an experimental nutrition intervention study, Wozniak et al. (2013) conducted a randomized double blinded, placebo-controlled trial of oral choline supplementation in children with FASDs, aged 2.5 to 4.9 years. Twenty children drank 4 ounces of a juice mix daily that contained either 500 mg of choline or placebo. This phase 1 study found a high tolerability and feasibility with choline supplementation in children with FASDs, aged 2 to 5 years. The next phase of this study will further evaluate choline intervention in relation to effects on cognition in the children.

As part of a choline supplementation study, Fuglestad et al. assessed the dietary intake of 31 children with FASDs, aged 2.5 to 4.9 years (Fuglestad et al., 2013). Information on dietary intake was recorded three times through Automated Self-Administered 24 hour Diet Recall with the collected data compared to the Dietary Reference Intakes and national dietary intake data of children, aged 2 to 5 years. Results showed that over half of the children with FASDs had diets with levels of calcium, choline, n-3 fatty acids, fiber, vitamin D, vitamin K, and vitamin E below the RDA or AI (Fuglestad et al, 2013, p. 873).

In similar fashion, Werts et al. (2014) examined the eating behaviors and diet in children, aged 3.9 to 15.1 years, referred to an FASD diagnostic center, by using a caregiver-reported dietary behavior questionnaire, 24-hour food recall, and nutrition interview with a dietitian. Of the 19 children evaluated, 79% met the criteria for FASD. Analysis revealed that the children with FASDs had recurring nutrition related problems, such as constipation, picky or selective eating, poor appetite, constant snacking, and lack of satiety. It was also noted in this group that the girls tended to be obese, while the boys were smaller or underweight. Diet intake analysis of the children's consumption found high levels of sugar and vitamin A, along with inadequate dietary levels of key micronutrients, such as vitamin D, choline, vitamin E, beta carotene, and the essential fatty acids.

Along with the scientific evidence, there are multiple anecdotal indications of behavioral and eating or nutritional-related problems in children with FASDs, aged 3 to 5 years, noted in various online FASD publications and FASD websites (NOFAS, 2012; Rajwani, n.d.). A booklet for parents/caregivers describes problems in preschool children with FASDs as having: A lack of interest in food, poor sleep habits, decreased motor coordination, lagging in expressive speech development, hyperactive, unable to adapt appropriately to change, and often throws temper tantrums (Graefe, Ross, & Julien, 1999; Russell, 2011). Similarly, from the National Organization on Fetal Alcohol Syndrome (NOFAS) website, there were behavior and feeding or eating problems characterized under the section, *FAS/FASD through the Lifespan: Strategies for Living: Toddlers* (NOFAS, 2012). This site commented that young children may experience the following: Poor memory, hyperactivity, delayed motor skills, the inability to sit still, poor appetites,

food sensitivities to texture, difficulty distinguishing food temperatures, and dental problems. These notations appear to suggest there are eating problems or difficulties in young children with FASDs.

Individuals who have neurological disorders or intellectual disability (ID) are reported to have an increased incidence of malnutrition and feeding problems (Gravestock, 2000). Since children with FASDs often have cognitive deficits, it would appear that they are at an increased risk for malnutrition and atypical eating behaviors. Many of the co-occurring mental health disorders diagnosed in children with FASDs are also known to have associated nutritional problems, such as the selective eating problems in children with ASD (Nadon et al., 2011). For example, children with ASD, due to an inability to properly interpret sensory stimuli, have difficulty with motor and functional living skills involved with self-care and eating (Jasmin et al., 2009). One study assessing sensory processing and eating problems in children with ASD found that 65% of participants, aged 3 to 10, had eating problems associated with sensory abnormalities related to the odor, taste, and/or texture of foods (Nadon et al., 2011, pp. 105 - 107).

Although many of the prenatal effects from maternal alcohol consumption have been investigated, there is limited research on the eating behaviors and nutritional issues present in young children with FASD. Knowledge about the feeding of children with FASDs is important since this will aid in the development of effective pediatric nutrition interventions and parental nutrition education to limit or reduce FASD adverse outcomes. In the identification of problem behaviors, assessment tools, such as standardized parent/caregiver report questionnaires, can be instrumental in the characterization of atypical general and eating behaviors of preschool-aged children with FASDs.

Assessment of Eating and General Behaviors in Early Childhood

Various types of instruments or measures are available to assess the different general behavior and feeding problems that can occur during early childhood development, such as difficulties with cognition, language, social competence, adaptation, and eating (Achenbach & Rescorla, 2000; Wardle et al., 2001). Assessments evaluating atypical childhood behaviors may acquire data through mixed-method procedures, such as with questionnaires and focus groups. Since parents/caregivers most likely know more about their children's functioning in different settings and at longer times than others involved with the children, parent/caregiver reported checklists or questionnaires are commonly used instruments to obtain data on the behaviors of children, aged 3 to 5 years. The CEBQ and CBCL are the two validated assessment tools or questionnaires used in this research. To expand the assessment approach, focus groups are a means of gathering qualitative information about targeted behaviors from experts in the field (Balachova, Bonner, Isurina, & Tsvetkova, 2007). Healthcare providers administer a variety of pediatric FASD care/services and, through discussion groups, can impart valuable insight into the behaviors that affect eating in preschool-aged children with FASDs. Questionnaires and focus groups are commonly used methods to collect data in research and have previously been used to investigate childhood nutrition and eating behavior (Cullen, Baranowski, Rittenberry, & Olvera, 2000; Rockett & Colditz, 1997).

Children's Eating Behavior Questionnaire

The Children's Eating Behavior Questionnaire (CEBQ), designed by Wardle and colleagues, defines the patterns of eating in young children, aged 2 through 7 years (Wardle et al., 2001). The intent of the developers was to provide a multi-dimensional standardized instrument to evaluate habitual childhood eating behaviors, most notably in relation to excessive body weight development. The groundwork of the questionnaire's content started with information from prior studies on eating behaviors, combined with responses from open-ended parental interviews about the eating styles of their children. Finalization of the CEBQ format came as the result of data analyses from three different samples of families with preschool children.

The CEBQ is a parent/caregiver-reported assessment instrument with 35 items, grouped into eight constructs or subscales that classify and evaluate how children eat (Wardle et al., 2001). The subscales contain items in regards to *Food Responsiveness* (FR, 5 items), *Enjoyment of Food* (EF, 4 items), *Desire to Drink* (DD, 3 items), *Satiety Responsiveness* (SR, 5 items), *Food Fussiness* (FF, 6 items), *Emotional Overeating* (EOE, 4 items), *Emotional Undereating* (EUE, 4 items), and *Slowness in Eating* (SE, 4 items). The CEBQ subscales describe behaviors or factors that may influence the child's nutrition, eating, and weight, as the following: FR and EF are subscales indicating there are environmental cues that influence dietary intake; DD captures the child who has an increased desire or need for fluids; SR determines how much the child controls appetite based on energy requirements; FF represents the child's avoidance of particular foods that may lead to poor variety in the diet; EOE and EUE reflect whether the amount of food eaten is increased or decreased when the child is experiencing stress; and SE defines a reduced food intake secondary to a lack in the enjoyment of eating food.

From the eight subscales or constructs, there is formation of two main responsive groups to represent the broader behavioral dimensions of *Food Approach* or *Food Avoidant* (Wardle et al., 2001). In the category of Food Approach, the subscales are FR (e.g., *My child's always asking for food*), EF (e.g., *My child is interested in food*), DD (e.g., *If given the chance, my child would always be having a drink*), and EOE (e.g., *My child eats more when anxious*). The subscales that represent Food Avoidance are SR (e.g., *My child leaves food on his/her plate at the end of the meal*), SE (e.g., *My child eats slowly*), FF (e.g., *My child is difficult to please with meals*), and EUE (e.g., *My child eats less when s/he is angry*). The developers report the subscales, within each group, coherently cluster with a negative correlation between the groups of Food Approach and Food Avoidant.

Since its development, the CEBQ has become an assessment instrument used in studies evaluating pediatric eating behavior (Svensson et al., 2011). It has received validation in both Western and non-Western countries. Research with the questionnaire includes investigating eating styles of children in relation to various health conditions and associations. At this time, it appears caregivers of children with FASDs, aged 3 to 5 years, have not participated in a research project using the CEBQ. However, there are responses reported from caregivers of preschool children in association with other concerns.

As an example, with the rise in obesity rates, there is interest in identifying factors that influence eating behaviors leading to excess adipose tissue in children (Haycraft, Farrow, Meyer, Powell, & Blissett, 2011). In a 2011 study by Haycraft et al., completion of the CEBQ by mothers of children, aged 3 to 8 years, contributed to evaluating the

effects of temperament traits on pediatric eating behavior and, subsequently, on BMI. Analysis disclosed that a higher BMI in the children had greater association with the CEBQ Food Approach subscales but the child's temperament traits were not related to BMI.

Another study using the CEBQ evaluated eating behavior, BMI, and maternal feeding practices targeting children, aged 2 to 4 years old (Gregory, Paxton, & Brozovic, 2010). The maternal feeding practices consisted of the pressure to eat, restriction, monitoring, and modeling of healthy eating. The study concluded that eating behavior in the children was influenced by maternal feeding practices; however, prospectively, the child's BMI was not.

Additionally, with the goal to better define the characteristics or profile of a fussy or picky eater, children, aged 4 years old, underwent assessment with the CEBQ (Tharner et al., 2014). The researchers felt that, during childhood, it was important to identify fussy or picky eating since it may result in problems with underweight status and/or micronutrient deficiencies affecting growth and development. It was found that, with fussy or picky eating, there were higher scores in the items of Food Fussiness, Slowness in Eating, and Satiety Responsiveness in comparison with lower scores in Enjoyment of Food and Food Responsiveness.

Child Behavior Checklist 1.5-5

From the work of Dr. Thomas Achenbach, the Achenbach System of Empirically Based Assessment (ASEBA) has checklists to evaluate emotional and behavioral problems in relation to psychopathology exhibited in early childhood (Achenbach &

Rescorla, 2000). Currently, the Child Behavior Checklist 1.5-5, redefined in 2000 from the 1992 Child Behavior Checklist/2-3, is often used in the assessment of preschool children. By revising the previous checklist, this increased the assessment age range to 1.5 to 5 years from the prior age range of 2 to 3 years. In association with the CBCL/1.5-5, there is a Caregiver-Teacher Report Form and a Language Development Survey.

The CBCL/1.5-5 is a standardized parent/caregiver-completed survey designed at a 5th grade reading level, which screens for variation in the functioning of children. It can be administered via hard copy or online (Achenbach & Rescorla, 2000). This structured rating scale assesses children 18 months to 5 years, 11 months of age behaviors over the last 2 months and takes around 10 to 20 minutes for the parent/caregiver to complete. To identify problem behaviors, the CBCL/1.5-5 generates profiles on the following three aggregate or broadband syndromes: Internalizing Problems (anxiety; disruptive items from the child), Externalizing Problems (aggression; disruptive items from the child's environment), and Total Problems (overall difficulties in behaviors).

Along with the broadband groupings, the CBCL/1.5-5 is further subdivided into two scales, defined as the syndrome scales and the DSM-oriented scales (Achenbach & Rescorla, 2000). The seven narrow-band syndrome scales, empirically derived through factor analysis, are as follows: The Emotionally Reactive (9 items), Anxious/Depressed (8 items); Somatic Complaints (11 items), and Withdrawn syndromes, which represent the Internalizing Problems; and the Attention Problems (8 items) and Aggressive Behavior (19 items), which form the Externalizing Problems; and Sleep Problems (13 items). The five scales related to DSM-V diagnostic criteria, as defined by expert clinical consensus, are the following: Affective Problems, Anxiety Problems, Pervasive

Developmental Problems, Attention Deficit/Hyperactivity Problems, and Oppositional Defiant Problems. In addition to the scaled items, there are open-ended questions that allow the parent/caregiver to describe the following: Other problems or disabilities the child may have; their major concerns about the child; and the things that are best about the child.

Since the CBCL/1.5 has both screening and diagnostic measures, it has been used in prior FASD research, such as in comparing problem behaviors and sensory processing in children with FASDs (Franklin et al., 2008). As reported by the parents/caregivers in a study by Franklin et al., children with FASDs, aged 5 to 10 years, frequently have difficulties in behavior and sensory processing. There are also studies by Nash and colleagues that have investigated the effectiveness of using the CBCL in the diagnosis of FASD through behavioral phenotype identification (Nash et al., 2006; Nash, Sheard, Rovet, & Koren, 2008). Based on the previous Nash studies, items of the CBCL were constructed into a screening instrument, designated as the Neurobehavioral Screening Test (NST) (Nash et al., 2013). Researcher demonstrated the NST had high sensitivity and specificity in the identification of the neurobehavioral phenotype in children with FASDs, aged 4 to 6 years (7 NST items), and aged 6 to 13 years (10 NST items) when compared to normal controls, children with ODD/CD/or ADHD, or referred children without a diagnosis (Breiner, Nulman, & Koren, 2013; Nash et al., 2013).

Combined Use of CEBQ and CBCL in Research

The CEBQ and CBCL have been used successfully together in research projects investigating behaviors and associated factors in young children (6 months to 47 months)

in relation to eating (Mackenbach et al., 2012; Velders et al., 2012). As part of the Generation R Study, Velders et al. (2012) evaluated the effects of the *FTO* minor allele at rs9939609 on eating behavior, BMI, emotional control, and ADHD in preschoolers, while Mackenbach et al. (2012) investigated the relationship between BMI and problems with emotions and behaviors in early childhood. Another separate prospective study is being proposed in Germany by Grube et al. to use the CEBQ and CBCL when examining risk factors involved in parents with obesity and the development of obesity in their children (Grube et al., 2013).

Summary

While many of the studies on children with FASDs have small sample sizes and/or limited age ranges, the results strongly suggest that there are manifestations of FASD that affect nutrition and eating (Jirikowic et al., 2008; Van Dyke, Mackay, & Ziaylek, 1982). Several characteristics of FASD, such as abnormal physiology, structural anomalies, poor motor control, and co-occurring disorders (for example autism) have associations with difficulties in food consumption and poor nutrition (Nanson, 1992; Uc et al., 1997). Furthermore, the use of growth delay and central nervous system dysfunction as diagnostic criteria for FASD suggests that nutrition deficits may be a major co-morbidity of this syndrome (U.S. Department of Health and Human Services, 2009). Given these indications, it appears children with FASDs would have difficulty with eating, which may stem from either primary or secondary causes; however, there have been few systematic investigations of eating behavior in children with FASDs, aged 3 to 5 years. In summation, the Academy of Nutrition and Dietetics recommends that nutrition is vital in the care of young children, especially the offering of nutrition services

to children with developmental disabilities and special health care needs (Van Riper & Wallace, 2010). The offering of nutrition services would apply to children with FASDs, aged 3 to 5 years, who may have developmental disabilities and special health care needs.

CHAPTER III

ATYPICAL EATING BEHAVIORS IDENTIFIED IN CHILDREN WITH FETAL ALCOHOL SPECTRUM DISORDERS, AGED 3 to 5 YEARS, USING THE CHILDREN'S EATING BEHAVIOR QUESTIONNAIRE IN A CROSS-SECTIONAL CAREGIVER-REPORTED ONLINE SURVEY

ABSTRACT

Background Children with fetal alcohol spectrum disorders (FASDs), aged 3 to 5 years, have physical, behavioral, and functional problems. Because of alcohol-related deficits, the children are at risk for malnutrition; yet, little is known about how FASD affects eating behaviors and nutrition.

Objectives The purpose of this study was to identify atypical eating behavior in children with FASDs, aged 3 to 5 years, and associations with socio-demographic and anthropometric characteristics.

Design This descriptive cross-sectional study gathered data from a caregiver-reported online survey targeting the eating behavior of children with FASDs, aged 3 to 5 years.

The survey included the Children's Eating Behavior Questionnaire (CEBQ), a socio-demographic questionnaire, and reports of children's anthropometric measurements.

Participants/setting Seventy-four caregivers qualified for the study with nine having two children with FASDs. Responses to survey questions varied since caregivers had permission to omit any question.

Main outcome measures Outcomes included CEBQ subscale scores, caregiver and children socio-demographic characteristics, and *z*-scores of the children anthropometric measurements.

Statistical analyses Descriptive statistics, Pearson's correlations, *t*-tests, and analysis of variance were performed to identify atypical eating behaviors. When indicated, post hoc pairwise comparisons with Tukey adjustments were conducted.

Results Compared to norms, study children scored higher in Desire to Drink, Food Responsiveness, Emotional Overeating, and Food Fussiness, and lower in Enjoyment of Food. There was greater Enjoyment of Food with larger families and in Food Avoidance with college-educated caregivers. Even though there were no significant relationships between the CEBQ subscales and BMI percentiles of underweight and overweight/obesity, study children with a low birth weight were more responsive to stimulators of food intake.

Conclusions Children with FASDs, aged 3 to 5 years, have atypical eating behaviors characteristic of maladaptive appetites, overeating under stress, selective eating, slowness in eating, and an excessive need for drinks, in comparison with a normative sample.

Introduction

Children with fetal alcohol spectrum disorders (FASDs) face a lifetime of difficulties from various problems that result from prenatal alcohol exposure.¹ Since alcohol is a neurobehavioral teratogen, it has been proposed the array of the effects in FASD may be from altered epigenetic mechanisms.² The effects caused by maternal alcohol consumption can present as physical, neurological, and/or behavioral abnormalities, depending on the timing, frequency, and quantity of maternal alcohol intake during gestation.^{3,4} Due to the alcohol-related injuries, children with FASDs are at increased risk for nutrition and eating problems.⁵

Fetal alcohol syndrome (FAS), recognized as one of the foremost causes of preventable intellectual disability in the United States, is the severest condition from prenatal alcohol exposure.^{6,7} Although not a diagnostic term, fetal alcohol spectrum disorders (FASDs), which includes FAS, represent the entire range of permanent disabilities occurring from maternal alcohol consumption.⁸ FASD has a prevalence of approximately 10 cases per 1,000 live births in the U.S, which is higher than rates of Down's syndrome (1 per 1,000 live births) and Spina Bifida (1 to 2 per 10,000 live births).⁹⁻¹¹

Even though growth deficiency and low birthweight are common in FAS, studies have shown overweight and obesity present in children with FASDs, suggestive of a dichotomy in eating difficulties.¹²⁻¹⁴ While eating problems can occur in children with normal development, children that have neurological, physical, or behavioral impairments are far more prone to have persistent challenges in nutrition and eating leading to nutrient deficiency and weight issues.¹⁵ Recent studies have described

irregularities in the nutrition and eating behaviors of children with FASDs, such as dietary deficiencies, poor appetite, diets high in sugar, abnormal mastication, and selective eating.¹³ In addition, many symptoms associated with FASD, such as abnormal gastrointestinal function, structural anomalies of the lip/palate, poor motor skills, and mental health disorders, can give rise to an inadequate nutritional intake.^{5,16,17} Yet, only a few studies have specifically examined eating behaviors and the influence on weight in children with FASDs, particularly aged 3 to 5 years old.^{13,18}

Since a child needs to eat properly to grow up, learn, and interact socially with others, it is important to define abnormal eating behaviors in children to assure adequate nutrition and proper weight.¹⁹ Assessment instruments, such as the Children's Eating Behavior Questionnaire (CEBQ), are available to characterize atypical eating behaviors in young children.²⁰ Many studies have used caregiver-reported questionnaires as a method of data collection regarding children.²¹⁻²³ Caregivers, who are the primary caretakers, can provide invaluable first-hand insight on the specific eating behaviors encountered in children with FASDs, especially those aged 3 to 5 years.¹³

The *hypothesis* of the study was that caregivers would report atypical eating behavior in children with FASDs, aged 3 to 5 years. The aim was to describe eating behavior problems in children with FASDs at an age when the child becomes an independent eater (aged 3 to 5 years old) and a critical time for nutrition in brain development.^{19,24} This is particularly important since neurological impairments are predominant adverse outcomes in FASD.^{3,25} Analysis included associations and/or differences in the children's eating behaviors in relation to caregiver/children socio-demographic characteristics, children's anthropometric measurements, and norms of a typically developing population as

assessed by the CEBQ.²⁰ This research was part of the project, *Eating Behavior in Children with FASDs: A Mixed Methods Study*, which investigated the eating behavior of children with FASDs, aged 3 to 5 years, using an online survey of FASD caregivers and focus groups of professionals in FASD pediatric healthcare. The goal of the study was to identify atypical eating behaviors for development of future nutrition interventions to reduce the adverse effects of FASD on childhood nutrition, growth, and function.

METHODS

Research Design and Participants

This descriptive study consisted of a cross-sectional online survey for caregivers of children with FASDs, aged 3 to 5 years. Through convenience sampling, recruitment of caregivers began on August 8, 2013 and ended on January 20, 2015. Caregivers were recruited through electronic communications with attached caregiver invitation flyers, which were sent to FASD websites (e.g., National Organization on FAS, 2012), government organizations, healthcare professionals, child study centers, and adoption agencies. An additional procedure in participant recruitment was through the snowball sampling approach with survey respondents and contacts asked to refer the survey to other caregivers of children with FASDs, aged 3 to 5 years. For this study, the term, caregivers, represented adults providing primary care at home to children with FASDs. Participants met inclusion criteria by responding to forced-answer questions that they were at least 18 years of age and had at least one child with FASD between the ages of 3 to 5 years. Male or female caregivers of the children could include, but were not limited

to, biological, adoptive, or foster parents, and relatives. The survey accommodated caregivers having up to four children with FASDs.

The data collection for the study was through *Qualtrics* software (*Qualtrics*© 2015, Provo, UT). Since the survey did not collect identifying information, the Oklahoma State University Institutional Review Board approved the study with an exemption for the signature requirement. Upon acknowledging consent on the cover page and answering the qualification questions correctly, respondents had access to the survey link.

Survey Response Rate and Sample Size

Of the 290 viewing the survey cover page, 143 (49%) were caregivers of children with FASDs. From the 143 caregivers, there were 74 caregivers (51%), who qualified for the study by having at least one child with FASD between the ages of 3 to 5 years. Nine (12%) of the caregivers had a second child in the target age range. When participating in the study, caregivers had the choice of stopping at any time or omitting questions during the course of the survey, if desired; hence, sample sizes per questionnaire item/subscales of the survey vary (sample sizes indicated on the study tables). Due to this fact, caregiver data in reference to the socio-demographic questionnaire vary from 49 (66%) to 74 (100%) responses. There were a total of reported data on 80 children with the socio-demographics and CEBQ items ranging from 63 (79%) to 80 (100%) of responses since three of the second children with FASDs were without reported data. As calculated by our statistician, demonstrations of power in the study to find the observed effect size significant ranged from 0.37 for the emotional undereating in 3 year olds and 0.87 for the food responsiveness in boys.

Data Collection Measures

In the larger study, the online caregiver survey consisted of socio-demographic questions, children anthropometric measurements, and two validated questionnaires, the Children's Eating Behavior Questionnaire (CEBQ), which is an instrument assessing eating styles of young children, and the Child Behavior Checklist (CBCL), which evaluates general behavioral problems in children.^{20,26,27} This study included the CEBQ, the socio-demographic questionnaire, and caregiver-reported anthropometric measurements of the children.

Socio-Demographic Questionnaire. Questions in the socio-demographic questionnaire, drawn from U.S. 2010 population census, were established after consultation with a statistician.²⁸ The demographic questions requested information, such as age, sex, and ethnicity, about the caregivers and children with FASDs.

Children Anthropometric Measurements. Anthropometrics for the children with FASDs were caregiver-reported measurements, which included the children's birth weight, current weight, and current height. Birthweight was categorized as a low birthweight of < 2.5 kg. Body mass index (BMI) was calculated as weight in kilograms divided by the square of the height in meters (kg/m²). After adjusting for age and sex, z-scores and percentiles were determined for weight, height, and BMI, using the online CDC software tool, Epi Info 7™ 7.1.5 (March 15, 2015, Atlanta, GA), and based on the reference data from US 2000 CDC growth charts.²⁹ BMI percentiles were categorized as underweight (BMI < 5th percentile), normal weight (BMI ≥ 5th percentile to < 85th percentile), and overweight/obese (BMI ≥ 85th percentile to 100th percentile).³⁰ Children

with BMI percentiles in the overweight/obese categories were grouped together due to small sample sizes.

Children's Eating Behavior Questionnaire. The CEBQ, a parent/caregiver-reported measure, consists of eight subscales (35 items) and has documented internal validity with good test-retest reliability.²⁰ This questionnaire can be completed by respondents in approximately 15 minutes or less and has a response format of a 5-point Likert-type scale. The rating of each item in a subscale is *never* (1), *rarely* (2), *sometimes* (3), *often* (4), and *always* (5).

The CEBQ provides assessment in the following subscales: Food Responsiveness (FR, eating in response to environmental cues, 5 items), Enjoyment of Food (EF, desire to eat, 4 items), Desire to Drink (DD, desire to carry around a drink, mostly sugar-sweetened, 3 items), Satiety Responsiveness (SR, regulating a decrease in food intake after eating, 5 items), Food Fussiness (FF, selective in dietary choices with rejection of new foods, causing inadequate variety in the diet, 6 items), Emotional Overeating (EOE, increased eating in response to negative emotions or stress, 4 items), Emotional Undereating (EUE, decreased eating in response to negative emotions or stress, 4 items), and Slowness in Eating (SE, a meal lasting over 30 minutes from a lack of food enjoyment or interest resulting in decreased food intake, 4 items).²⁰ Examples of subscale items are as follows: *My child's always asking for food* (FR), *My child enjoys eating* (EF), *If given the chance, my child would always be having a drink* (DD), *My child gets full up easily* (SR), *My child enjoys tasting new foods* (FF), *My child eats more when anxious* (EOE), *My child eats less when s/he is upset* (EUE), and *My child finishes his/her meal quickly* (SE). The following items in the subscales underwent reverse coding: *My child has a big appetite*

(SR), *My child enjoys tasting new foods* (FF), *My child enjoys a wide variety of foods* (FF), *My child is interested in tasting food s/he hasn't tasted before* (FF), and *My child finishes his/her meal quickly* (SE).

For this study, the reliability statistic, Cronbach's alpha, was determined for each CEBQ subscale and ranged from 0.79 to 0.94. In the Wardle et al. study, using a sample of 320 parents from eight primary school nursery classes and nursery schools (urban and suburban), the Cronbach's alphas ranged from 0.74 to 0.91.²⁰ The study's CEBQ internal consistency appeared acceptable to high for all subscales and comparable to Wardle et al. in 2001.

When developing the CEBQ, the subscales of Satiety Responsiveness and Slowness in Eating had similar factor loading in Principal Component Analysis (PCA) resulting in seven instead eight subscales.²⁰ However, the eight subscales were maintained in the CEBQ, since keeping the separation could yield a better description of the eating behaviors. Likewise, PCA in this study extracted 7 components out of the 35 CEBQ items as subscales with eigenvalues greater than one, which explained 42% to 80% of the variance. Following Wardle et al, the study analyses will also maintain eight subscales.

This study used, as a normative sample for comparison, a combination of samples 2 and 3 from the Wardle et al. study.²⁰ From eight (urban and suburban) nursery school and primary school nursery classes, sample 2 had 100 boys and 78 girls with a mean age of 4.2 ± 1.4 years. In sample 3, there were 111 boys and 97 girls with a mean age of 5.6 ± 1.5 years, recruited from six (urban) nursery schools and advertisement. The caregivers of the children in the normative sample were from a broad range of socio-demographic backgrounds.

The CEBQ identifies different dimensions in a child's eating style readily described by caregivers.²⁰ Many studies have utilized the CEBQ to examine eating and underweight or overweight/obesity.³¹⁻³³ It has also been employed in assessment of other conditions, such as problematic eating in young children with dental caries.²¹ The subscales, when grouped together, represent indicators that stimulate food intake (food approach) or inhibit food intake (food avoidance).²⁰ Higher subscale scores of Food Approach (EF, FR, EOE, and DD) depict a positive or stimulated response to food intake, which could lead to overweight/obesity.²⁰ Higher subscales scores of Food Avoidance (SR, SE, FF, and EUE) typify food restraint with tendencies toward being underweight.

Statistical Analyses

The *IBM SPSS Version 21.0 software* for *Windows* (SPSS, Inc, Chicago, IL) was used for data analyses, planned a priori. Descriptive statistics were conducted on all first and second children of the caregivers and then repeated without the second child of the caregivers. With the results between the two groups being similar, analysis of the study considered all of the children (child 1 and 2 of the caregiver) as one group. Missing responses were omitted from analyses and outliers were identified but not removed. Descriptive statistics summarized the socio-demographic profiles of caregivers and children with FASDs. Measurement variables of interval, nominal, ordinal, and Likert-type scales are in tables to display the distribution and frequency of outcomes. Two-tailed two population *t*-tests for independent samples were conducted combining the summary statistics from the Wardle et al. normative sample and the FASD data.²⁰ Cross tabulations were used to compare percentages of weight status between the children with FASDs to U.S. 2013 values, in which underweight and overweight were combined to assess

between normal and not normal percentages.³⁵ To identify atypical eating behaviors and associations, Pearson's correlations, independent samples *t*-tests, and analyses of variance were conducted. If indicated, post hoc pairwise comparisons with Tukey adjustments were performed. Z-scores of the study children's weight, height, and BMI were compared to the U.S. reference population ($M = 0$) with one sample *t*-tests.²⁹ Due to the study being exploratory and that the eating behavior in children with FASDs has not yet been fully described, familywise error was not controlled and the number of analyses erred on the side of minimizing type II error. Using Cohen's conventions, correlations were interpreted as small (0.1 to 0.3), medium (0.3 to 0.5), and large (0.5 to 1.0).³⁴ Significance for analysis was set on a two-tailed *p* value < 0.05.

RESULTS

Descriptive Statistics of Socio-demographic Characteristics

Descriptive statistics of the caregivers and children socio-demographic characteristics are in Tables 1 and 2, respectively. Most caregivers (96%) responding to the online survey resided in the United States and the mean age of caregivers was 42.3 ± 8.1 years. The children's caregivers were college educated (46%), primarily unemployed (46%) or part-time employed (28%), Caucasian (90%), and females (98%), who were married for the first time (61%). Of the caregivers, 85% were adoptive or foster parents to their child with FASD and approximately 12% were grandparents of the children. Considering household environment, the total number of people living in the caregiver's home ranged from 2 to 8 members with 43% in the 4 to 5 household member group. The children with

FASDs had a mean age of 4.3 ± 0.7 years with a higher percentage of the children being male (61%) and Caucasian (57%).

Table 1. Socio-demographic characteristics of the caregivers, who had children with FASDs, aged 3 to 5 years, that participated in the online survey ($n = 74$)

| | <i>n</i> (%) |
|---|--------------|
| Sex | |
| Male | 1 (2) |
| Female | 50 (98) |
| Relationship to child | |
| Biological parent | 1 (1) |
| Adoptive parent or Foster parent | 63 (85) |
| Grandparent | 9 (12) |
| Other | 1 (2) |
| Ethnicity | |
| African American | 1 (2) |
| Asian | 2 (4) |
| Hispanic | 1 (2) |
| Caucasian | 46 (90) |
| Native American including Alaskan Native | 1 (2) |
| Marital status | |
| Single, never married, Single divorced, and Single, widowed | 9 (18) |
| Married, first time | 31 (61) |
| Remarried | 11 (21) |
| Number of members per household | |
| 2 and 3 members | 13 (26) |
| 4 and 5 members | 21 (43) |

| | |
|--|---------|
| 6, 7, and 8 members | 15 (31) |
| Education | |
| 11th or 12th grade, Some Vo-tech or College classes, or Vo-tech graduate | 16 (32) |
| College graduate | 23 (46) |
| Postgraduate degree | 11 (22) |
| Employment status | |
| Unemployed, Not employed (disability), Retired, and Unknown | 23 (46) |
| Employed Part-time | 14 (28) |
| Employed Full-time | 13 (26) |
| Total 2012 family income | |
| Unknown | 1 (2) |
| Under \$30,000 | 8 (16) |
| \$31,000 - \$75,000 | 20 (40) |
| Greater than \$75,000 | 21 (42) |
| Residence | |
| United States | |
| North-east region 6 (12) | |
| New Jersey (2), New York (3), Pennsylvania (1) | |
| Midwest region 14 (29) | |
| Illinois (1), Indiana (1), Michigan (3), Minnesota (7), Wisconsin (1) | |
| West region 13 (26) | |
| Alaska (1), Arizona (1), California (8), Colorado (1), Washington (2) | |
| South region 14 (29) | |
| Arkansas (2), Florida (1), Maryland (1), North Carolina (5), Texas (5) | |
| International 2 (4) | |
| Alberta, Canada (1), Scotland (1) | |

Table 2. Socio-demographic characteristics of the children with FASDs, aged 3 to 5 years old, as reported by the caregivers in the online survey ($n = 80$)

| | <i>M±SD^a</i> |
|---|-------------------------|
| Birthweight (kg) | 2.7±0.7 |
| Boys | 2.8±0.7 |
| Girls | 2.6±0.6 |
| Z-scores: Overall, gender, and age group | |
| Weight-for-age z-score | 0.28±1.1 |
| Boys | 0.24±1.3 |
| Girls | 0.36±0.7 |
| 3-year-olds | 0.66±0.9 |
| 4-year-olds | 0.09±1.2 |
| 5-year-olds | 0.26±1.2 |
| Height-for-age z-score | 0.10±2.0 |
| Boys | -0.25±2.2 |
| Girls | 0.80±1.3 |
| 3-year-olds | 0.13±1.0 |
| 4-year-olds | -0.39±2.2 |
| 5-year-olds | 0.46±2.2 |
| BMI z-score | 0.22±1.9 |
| Boys | 0.39±2.1 |
| Girls | -0.10±1.2 |
| 3-year-olds | 0.39±1.3 |
| 4-year-olds | 0.27±2.2 |
| 5-year-olds | 0.08±1.9 |

| | <i>n</i> (%) |
|---|--------------|
| Sex | |
| Boys | 49 (61) |
| Girls | 31 (39) |
| Age groups | |
| 3-year-olds | 14 (18) |
| 4-year-olds | 30 (37) |
| 5-year-olds | 36 (45) |
| Ethnicity | |
| African American | 9 (15) |
| Asian | 2 (3) |
| Hispanic | 8 (13) |
| Caucasian | 35 (57) |
| Native American, including Alaskan Native | 5 (8) |
| Other race | 3 (4) |
| Birthweight \geq 2.5 kg | 16 (40) |
| Boys | 9 (56) |
| Girls | 7 (44) |
| Birthweight $<$ 2.5 kg | 24 (60) |
| Boys | 15 (63) |
| Girls | 9 (37) |
| BMI percentile groups | |
| Underweight | 6 (16) |
| Boys | 5 (83) |
| Girls | 1 (17) |
| Normal weight | 21 (57) |

| | |
|-------------------------|---------|
| Boys | 11 (52) |
| Girls | 10 (48) |
| Overweight/obese | 10 (27) |
| Boys | 8 (80) |
| Girls | 2 (20) |

^a $M \pm SD$ = mean \pm standard deviation.

Descriptive Statistics of Children Anthropometric Measurements

Table 2 also includes caregiver-reported anthropometric measurements of the children with FASDs, aged 3 to 5 years. The average birth was 2.70 ± 0.70 kg, with 60% in the low birthweight category (birth weight < 2.50 kg). In the BMI percentile groups, there were 16% ($n = 6$; 5 boys, 1 girl) in the underweight, 57% ($n = 21$) in the normal weight, and 27% ($n = 10$; 8 boys, 2 girls) in the overweight/obese groups.

Descriptive Statistics of CEBQ Subscales

As indicated in Tables 3 and 4, descriptive statistics of the CEBQ revealed the subscale, Desire to Drink, was the most commonly reported eating behavior problem for children with FASDs, aged 3 to 5 years. The Slowness in Eating subscale in 4-year-olds and Food Fussiness in 5-year-olds and boys were also predominating eating behaviors. Emotional Overeating was the least reported eating behavior overall, and by sex and age.

Table 3. Descriptive statistics of CEBQ subscales for all children with FASDs and by gender with independent samples *t*-tests by gender between children with FASDs, aged 3 to 5 years, as reported by caregivers, and a normative sample of children^a in the same age range

| CEBQ | All Children with FASDs | | | Boys with FASDs | | Boys of Normative Sample ^b | | <i>p</i> for <i>t</i> -test | Girls with FASDs | | Girls of Normative Sample ^b | | <i>p</i> for <i>t</i> -test |
|------------------------|-------------------------|--------------|----------|-----------------|----------|---------------------------------------|----------|-----------------------------|------------------|----------|--|----------|-----------------------------|
| | Cronbach's α | $M \pm SD^a$ | <i>n</i> | $M \pm SD^a$ | <i>n</i> | $M \pm SD^a$ | <i>n</i> | | $M \pm SD^a$ | <i>n</i> | $M \pm SD^a$ | <i>n</i> | |
| EF^c | 0.94 | 3.2±1.1 | 69 | 3.1±1.0 | 45 | 3.6±0.8 | 215 | 0.001* | 3.4±1.3 | 24 | 3.6±0.9 | 181 | 0.443 |
| EOE^d | 0.84 | 2.1±0.9 | 68 | 2.2±1.0 | 44 | 1.8±0.6 | 215 | 0.018* | 2.1±0.9 | 24 | 1.8±0.6 | 181 | 0.112 |
| DD^e | 0.94 | 3.5±1.3 | 69 | 3.5±1.3 | 44 | 2.9±1.1 | 215 | 0.005* | 3.5±1.3 | 25 | 2.9±1.2 | 181 | 0.029* |
| FR^f | 0.93 | 2.8±1.3 | 68 | 2.7±1.2 | 44 | 2.3±0.8 | 215 | 0.044* | 3.0±1.3 | 24 | 2.2±0.8 | 181 | 0.008* |
| SR^g | 0.90 | 3.2±1.1 | 69 | 3.2±1.0 | 44 | 3.1±0.7 | 215 | 0.587 | 3.2±1.2 | 25 | 3.1±0.7 | 181 | 0.827 |
| SE^h | 0.92 | 3.4±1.2 | 67 | 3.4±1.2 | 44 | 3.1±0.8 | 215 | 0.159 | 3.4±1.3 | 23 | 3.2±0.8 | 181 | 0.554 |

| | | | | | | | | | | | | | |
|------------------------|------|---------|----|---------|----|---------|-----|--------|---------|----|---------|-----|-------|
| FFⁱ | 0.90 | 3.3±1.1 | 68 | 3.4±1.0 | 43 | 3.1±0.9 | 215 | 0.030* | 3.1±1.2 | 25 | 2.9±0.9 | 181 | 0.402 |
| EUE^j | 0.79 | 3.1±1.0 | 63 | 3.2±1.0 | 41 | 3.1±0.8 | 215 | 0.600 | 3.0±1.0 | 22 | 3.0±0.7 | 181 | 0.958 |

*. Correlation significant at the 0.05 level (2-tailed).

^a $M \pm SD$ = Mean \pm Standard Deviation.

^bWardle et al. (2001), page 968.

^cEF = Enjoyment of Food.

^dEOE = Emotional Overeating.

^eDD = Desire to Drink.

^fFR = Food Responsiveness.

^gSR = Satiety Responsiveness.

^hSE = Slowness in Eating.

ⁱFF = Food Fussiness.

^jEUE = Emotional Undereating.

Table 4. Descriptive statistics of the CEBQ subscales and independent *t*-tests by age between the children with FASDs, aged 3 to 5 years, and a normative sample of children^a in the same age range

| CEBQ | 3-year-olds with FASDs | | 3-year-olds of Normative Sample ^a | | <i>p for t-test</i> | 4-year-olds with FASDs | | 4-year-olds of Normative Sample ^a | | <i>p for t-test</i> | 5-year-olds with FASDs | | 5-year-olds of Normative Sample ^a | | <i>p for t-test</i> |
|------------------------|-----------------------------------|----------|--|----------|---------------------|-----------------------------------|----------|--|----------|---------------------|-----------------------------------|----------|--|----------|---------------------|
| | <i>M</i> ± <i>SD</i> ^b | <i>n</i> | <i>M</i> ± <i>SD</i> ^b | <i>n</i> | | <i>M</i> ± <i>SD</i> ^b | <i>n</i> | <i>M</i> ± <i>SD</i> ^b | <i>n</i> | | <i>M</i> ± <i>SD</i> ^b | <i>n</i> | <i>M</i> ± <i>SD</i> ^b | <i>n</i> | |
| EF^c | 3.4±1.2 | 12 | 3.6±0.9 | 76 | 0.527 | 3.2±1.2 | 25 | 3.3±0.9 | 102 | 0.722 | 3.1±1.1 | 32 | 3.8±0.8 | 81 | 0.001* |
| EOE^d | 2.2±1.1 | 13 | 1.7±0.7 | 76 | 0.109 | 2.1±0.9 | 24 | 1.7±0.6 | 102 | 0.063 | 2.2±1.0 | 31 | 1.8±0.5 | 81 | 0.037* |
| DD^e | 3.7±1.1 | 13 | 3.1±1.2 | 76 | 0.082 | 3.5±1.4 | 25 | 2.9±1.1 | 102 | 0.041* | 3.4±1.3 | 31 | 3.0±1.0 | 81 | 0.136 |
| FR^f | 2.8±1.2 | 13 | 2.2±0.8 | 76 | 0.078 | 2.8±1.4 | 24 | 2.1±0.7 | 102 | 0.014* | 2.7±1.2 | 31 | 2.3±0.7 | 81 | 0.068 |
| SR^g | 3.3±1.0 | 13 | 3.2±0.5 | 76 | 0.875 | 3.2±1.1 | 24 | 3.3±0.6 | 102 | 0.753 | 3.1±1.0 | 32 | 3.0±0.7 | 81 | 0.594 |
| SE^h | 3.3±1.3 | 12 | 3.4±0.7 | 76 | 0.820 | 3.9±1.1 | 24 | 3.4±0.8 | 102 | 0.068 | 3.0±1.2 | 31 | 3.1±0.7 | 81 | 0.714 |
| FFⁱ | 3.5±0.9 | 12 | 2.9±0.8 | 76 | 0.022* | 3.2±1.1 | 25 | 3.1±0.9 | 102 | 0.785 | 3.4±1.1 | 31 | 2.9±0.9 | 81 | 0.033* |

| | | | | | | | | | | | | | | | |
|------------------------|---------|----|---------|----|-------|---------|----|---------|-----|-------|---------|----|---------|----|-------|
| EUE^j | 2.8±1.0 | 11 | 3.3±0.8 | 76 | 0.143 | 3.2±1.0 | 24 | 3.1±0.8 | 102 | 0.806 | 3.2±1.0 | 28 | 3.0±0.6 | 81 | 0.258 |
|------------------------|---------|----|---------|----|-------|---------|----|---------|-----|-------|---------|----|---------|----|-------|

*. Significant at the 0.05 level (2-tailed).

^aWardle et al. (2001), page 968.

^b $M \pm SD$ = means±standard deviation.

^cEF = Enjoyment of Food.

^dEOE = Emotional Overeating.

^eDD = Desire to Drink.

^fFR = Food Responsiveness.

^gSR = Satiety Responsiveness.

^hSE = Slowness in Eating.

ⁱFF = Food Fussiness.

^jEUE = Emotional Undereating.

Correlations between CEBQ subscales

Similar to the findings of Wardle et al., the Food Approach (EF, EOE, DD, and FR) and the Food Avoidance (SR, SE, FF, and EUE) subscales within each group were positively inter-correlated; while, between the two main scales, the subscales were negatively correlated.²⁰ Large statistically significant negative correlations were observed between two of the Food Approach and two of the Food Avoidance subscales (EF to SR, EF to FF, FR to SR, and FR to FF). Correlations are in Table 6.

Relationships of CEBQ subscales to the Socio-demographic Characteristics, Anthropometric Measurements, and Normative Sample

As reported in Table 6, caregiver income was higher with larger households ($r = 0.34$, $p = 0.019$), higher education levels ($r = 0.36$, $p = 0.011$), and being married ($r = 0.28$, $p = 0.047$). Conversely, income level was lower with caregiver age ($r = -0.36$, $p = 0.018$).

There were no associations with employment, child age, or ethnicity.

Study children ($M = 3.4$, $SD = 1.18$, $M = 3.24$, $SD = 0.86$, respectively) living in households of 6 to 8 members enjoyed food [$F(2,45) = 3.97$, $p = 0.024$] and responded to food intake stimulators [$F(2, 42) = 2.33$, $p = 0.030$] more than the two and three member per household group ($M = 2.12$, $SD = 0.64$, $M = 2.44$, $SD = 0.64$, respectively). The four and five household member group ($M = 2.45$, $SD = 1.20$, $M = 2.68$, $SD = 0.80$, respectively) did not significantly differ from the other groups nor was there a statistically significant difference with Emotional Overeating between any groups. In overall eating styles [$F(2,37) = 3.67$, $p = 0.035$], caregivers with a college degree ($M = 3.75$, $SD = 0.54$) had children exhibiting greater Food Avoidance than children of

caregivers with the high school/Vo Tech degree ($M = 3.00$, $SD = 0.92$). There was no difference in children of caregivers with a postgraduate college degree ($M = 3.31$, $SD = 0.82$).

Table 5. Pearson's product-moment correlations between socio-demographic characteristics of the caregivers and children with FASDs, aged 3 to 5 years, in the study

| | <i>n</i> | 1. | 2. | 3. | 4. | 5. | 6. | 7. | 8. | 9. | 10. | 11. | 12. | 13. |
|------------------------------|----------|----|---------|-------|-------|--------|-------|-------|-------|-------|--------|--------|---------|--------|
| 1. Caregiver age | 45 | -- | -0.46** | 0.03 | 0.03 | -0.36* | -0.24 | 0.30 | 0.27 | -0.01 | 0.30 | 0.01 | 0.28 | 0.15 |
| 2. Household | 49 | | -- | -0.08 | -0.18 | 0.34* | 0.22 | -0.22 | 0.02 | -0.03 | -0.05 | -0.12 | 0.08 | 0.19 |
| 3. Education | 50 | | | -- | 0.15 | 0.36* | 0.10 | -0.18 | 0.04 | -0.18 | -0.11 | -0.22 | 0.16 | -0.26 |
| 4. Employment | 50 | | | | -- | 0.13 | -0.26 | 0.03 | -0.17 | -0.15 | -0.04 | -0.14 | 0.20 | -0.09 |
| 5. 2012 income | 50 | | | | | -- | 0.28* | 0.04 | -0.21 | 0.04 | -0.17 | 0.07 | -0.16 | -0.23 |
| 6. Marital status | 51 | | | | | | -- | 0.18 | -0.01 | 0.13 | 0.28 | 0.20 | -0.12 | -0.05 |
| 7. Children's age | 80 | | | | | | | -- | -0.10 | 0.11 | 0.55** | 0.59** | -0.07 | -0.01 |
| 8. WAZ ^a | 48 | | | | | | | | -- | 0.39* | 0.75** | 0.29 | -0.48** | 0.54** |
| 9. HAZ ^b | 37 | | | | | | | | | -- | 0.33* | 0.86** | -0.59** | 0.33 |
| 10. Current weight | 48 | | | | | | | | | | -- | 0.58** | 0.35* | 0.44* |
| 11. Current height | 46 | | | | | | | | | | | -- | -0.53** | 0.30 |
| 12. BMI <i>z</i> -score | 37 | | | | | | | | | | | | -- | 0.30 |
| 13. Birthweight ^c | 40 | | | | | | | | | | | | | -- |

*. Correlation significant at the 0.05 level (2-tailed).

** . Correlation significant at the 0.01 level (2-tailed).

^a WAZ = weight-for-age *z*-score.

^b HAZ = height-for-age *z*-scores.

^c Birthweight of study children.

Table 6. Pearson's product-moment correlations between CEBQ subscales and number of members in households of caregivers, who participated in the online survey, and birthweight of children with FASDs, aged 3 to 5 years, as reported by caregivers

| | <i>n</i> | 1. | 2. | 3. | 4. | 5. | 6. | 7. | 8. | 9. | 10. | 11. | 12. |
|------------------------------------|----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|------------|------------|------------|
| 1. EF^a | 69 | -- | 0.48** | 0.29* | 0.82** | -0.77** | -0.48** | -0.71** | -0.2 | 0.81** | -0.72** | 0.38* | 0.13 |
| 2. EOE^b | 68 | | -- | 0.32** | 0.62** | -0.42** | -0.29* | -0.38** | -0.07 | 0.74** | -0.40** | 0.30* | 0.33* |
| 3. DD^c | 69 | | | -- | 0.44** | -0.35** | -0.1 | -0.17 | -0.24 | -0.74** | 0.89** | 0.03 | 0.23 |
| 4. FR^d | 68 | | | | -- | -0.77** | -0.44** | -0.54** | -0.22 | -0.42** | 0.71** | 0.42** | 0.33* |
| 5. SR^e | 69 | | | | | -- | 0.57** | 0.59** | 0.52** | 0.67** | -0.26* | -0.24 | -0.25 |
| 6. SE^f | 67 | | | | | | -- | 0.35** | 0.12 | -0.56** | 0.77** | -0.21 | -0.40* |
| 7. FF^g | 68 | | | | | | | -- | 0.33* | -0.24 | 0.64** | -0.15 | 0.04 |
| 8. EUE^h | 63 | | | | | | | | -- | 0.92** | -0.70** | -0.27 | -0.05 |
| 9. FAPPⁱ | 66 | | | | | | | | | -- | -0.66** | 0.38* | 0.33* |
| 10. FAVO^j | 54 | | | | | | | | | | -- | -0.25 | -0.19 |
| 11. Household group | 47 | | | | | | | | | | | -- | 0.19 |
| 12. Birthweight^k | 40 | | | | | | | | | | | | -- |

*. Correlation significant at the 0.05 level (2-tailed).

** . Correlation significant at the 0.01 level (2-tailed).

^aEF = Enjoyment of Food.

^bEOE = Emotional Overeating.

^cDD = Desire to Drink.

^dFR = Food Responsiveness.

^eSR = Satiety Responsiveness.

^fSE = Slowness in Eating.

^gFF = Food Fussiness.

^hEUE = Emotional Undereating.

ⁱFAPP = Food Approach.

^jFAVO = Food Avoidance.

^kBirthweight of children.

The eating behavior differences by sex and age were examined within the study children. There were no differences in the CEBQ subscales by sex. When evaluating age [$F(2,5) = 4.53, p = 0.015$], there was significant relationship with age and Slowness in Eating in children. Post hoc comparisons (Tukey) found the 3-year-olds were slower in eating than the 5-year-olds but there was no difference in the 4-year-olds. Means and standard deviations are in the descriptive analysis in Table 3.

Moreover, the CEBQ subscales, Food Responsiveness ($r = 0.33, p = 0.036$), Emotional Overeating ($r = 0.33, p = 0.043$), and Food Avoidance ($r = 0.33, p = 0.038$) were positively associated with birthweight; while there was an inverse correlation of higher birthweight and lower Slowness in Eating, which reflects a faster eating rate as birth weight increased in the children ($r = -0.40, p = 0.043$). Children with low birthweight (< 2.5 kg) had higher scores in Food Responsiveness [$M = 2.37, SD = 0.83, M = 1.93, SD = 1.2$, respectively; $t(38) = 2.609, p = 0.013$] and Food Approach [$M = 3.00, SD = 0.81, M = 2.92, SD = 1.2$, respectively; $t(37) = 2.373, p = 0.023$] than children with birthweight equal to or greater than 2.5 kg. In addition, the children's birthweight was positively related to weight-for-age z -scores ($r = 0.54, p = 0.003$) and current weight ($r = 0.44, p = 0.016$) but was not significantly associated with age.

The study sample means for weight-for age z -score [$t(47) = 1.75, p = 0.087$], height-for age z -scores [$t(44) = 0.339, p = 0.736$], and BMI z -scores [$t(36) = 0.708, p = 0.484$] showed no statistical difference to U.S norms ($M = 0$), which were based on the CDC Growth Charts (2000). However, evaluation between anthropometric measurements by sex in the study children found that, in the height-for-age z -scores, boys were significantly shorter than the girls [$t(42.2) = -2.027, p = 0.049$]. There were no significant

findings between the CEBQ subscales and the weight-for-age z -scores, height-for-age z -scores, BMI z -scores, or BMI percentile groups.

In comparison of differences in low birthweight percentages, the percentage of low birthweight in the children with FASDs (60%) was significantly different than the U.S. 2013 percentage of low birthweight (8.0%) [$\chi^2(1) = 144, p = 0.0001$].³⁵ When comparing normal to not normal weight percentages (combined underweight and overweight percentages), the preschool-aged study children's percentages (55% and 46%, respectively) compared to the U.S. 2011 to 2012 percentages (74% and 26%, respectively) were significantly different [$\chi^2(1) = 4.27, p = 0.038$].³⁶

Comparisons were conducted between the children with FASDs, aged 3 to 5 years, and the normative sample of the Wardle et al. study.²⁰ By sex (Table 2), the boys with FASDs were significantly different in Emotional Overeating ($p = 0.018$), Desire to Drink ($p = 0.005$), Food Fussiness ($p = 0.030$), Food Responsiveness ($p = 0.044$), and Enjoyment of Food ($p = 0.001$) when compared to the normative sample of boys. Girls with FASDs, compared to the girls of the normative sample, were significantly different in Desire to Drink ($p = 0.029$) and Food Responsiveness ($p = 0.008$). When assessed by age (Table 3), there was statistically significant difference in Food Fussiness ($p = 0.022, p = 0.033$, respectively) between the 3- and 5-year-olds with FASDs and the 3- and 5-year-olds of the normative sample. The 4-year-old children with FASDs were significantly different from the 4-year-olds of the normative sample in Desire to Drink ($p = 0.041$) and Food Responsiveness ($p = 0.014$), while 5-year-olds with FASDs were significantly different in Enjoyment of Food ($p = 0.001$) compared to the normative sample of 5-year-olds. Means

and standard deviations, regarding comparisons between the children with FASDs, aged 3 to 5 years, and the normative sample, are in Tables 2 and 3.

DISCUSSION

To the investigators' knowledge, this study was the first to explore the eating behavior of children with FASDs, aged 3 to 5 years, using the CEBQ in an online survey. Most notably in the study, caregivers reported the children had atypical eating behaviors of abnormal appetite, emotional overeating, selective eating, slower eating, and an excessive need for drinks. Given that young children with FASDs exhibit atypical eating behaviors, it is important to evaluate nutritional status in FASD and provide early intervention to prevent malnutrition, especially during vulnerable times in brain development.

Childhood underweight and overweight/obesity are serious public health problems in need of early identification and intervention.^{35,36} The U.S. Department of Health and Human Services National Health and Nutrition Examination Survey estimated in 2011–2012 that, in children, aged 2 to 5 years, there were 3.2% underweight, 14.5% overweight, and 8.4% obese.³⁶ In the children with FASDs, aged 3 to 5 years, the percentages of normal to not normal weights differed from the U.S. estimates on weight status. Though the study sample size was small, the prevalence of underweight and overweight/obesity indicates a diversity of weight issues in FASD, which require further investigation.

To identify characteristics affecting childhood nutrition and weight, the CEBQ subscales describe the eating behavior of children that may lead to the development of underweight or overweight/obesity.²⁰ The growth and weight in children with FASDs

ranged above and below the normal reference parameters. In this study, 6% of children were below the 5th percentile in weight-for-age and 20% below the 5th percentile in height-for-age. In addition, within the study children, boys were significantly shorter than the girls, indicating a growth deficit by sex. However, in regards to *z*-scores, there were no differences between the weight-for-age *z*-scores and height-for-age *z*-scores in the study children and the U.S. norms (based on the 2000 CDC Growth Charts) or in CEBQ subscales.²⁹ Even though some preschool children with FASDs fall in normal growth patterns at this time, habitual atypical eating behavior could affect future growth development. Previous studies have found relationships between CEBQ subscales and BMI in children of typical development; however, there were no significant findings between the BMI *z*-scores or BMI percentile groups and the CEBQ subscale scores in the study children. This may be due to the small sample sizes or the differences in adiposity rebound in preschool children or the FASD condition itself.³⁷

Associations in anthropometrics were present with the CEBQ subscales and birthweight of the study children. Since children with FASDs of higher birthweight had a faster rate of eating, eventual excessive weight gain or obesity may be a consequence from eating too quickly.²⁰ Equally important, the percentage of low birthweight children in this study was significantly different than the national rate.^{14,38} There are implications that low birthweight and malnutrition play a role in long-term adult health consequences, such as obesity, because of alterations in epigenetic markers.³⁹ Results of this study found low birthweight in FASD was associated with stimulators of food intake, in which there is a higher tendency to eat when prompted by external food cues.²⁰ Since low birthweight is commonly associated with prenatal alcohol exposure, the finding is suggestive that some

atypical eating behaviors may be the result of epigenetic modifications from alcohol's teratogenic effects and/or maternal malnutrition.

Assessment of the CEBQ subscales and socio-demographic characteristics revealed positive and negative food intake eating behaviors in the study children. Stimulators of food intake were noted in children with FASDs, aged 3 to 5 years, who lived in larger families. One explanation is that larger families may offer a wider range and amount of foods at meals and snack times. Another may be that some children with FASDs have sensory processing disorders that lead them to either seek or avoid sensations.⁴⁰ Hence, if the children with FASDs are sensory seekers that live in larger families, the environmental conditions may be too stimulating, which may result in a heightened desire to eat, excessive eating under stress, and more external food cues that prompt eating, leading to excessive weight issues.²⁰ Conversely, study children with college-educated caregivers had higher Food Avoidance than with high school/Vo Tech educated caregivers. One explanation may be that caregivers with higher education have more exposure to nutrition information and practice greater restraint of food intake in an effort to avert overweight/obesity.⁴¹ Similar to the original CEBQ findings, differences were noted by age and not by sex.²⁰ In the study children, Slowness in Eating was more prevalent in 3-year-olds than 5-year-olds, which was akin to the normative sample in Wardle et al. with Slowness in Eating decreasing with age.

The preschool-aged children with FASDs were found to have atypical behaviors in both stimulators and inhibitors of eating when compared to a normative sample. There was identification of higher Desire to Drink and Food Fussiness in study children, which may influence dietary quality and quantity by increasing intake of sugar-sweetened beverages

and limiting the variety of food consumed.^{42,43} A recent nutrition study reported that children with FASDs, aged 4 to 14 years, had a diet high in simple sugars with deficiencies in micronutrients and a feeding pattern of selective eating.¹³ Consumption of sugar-sweetened beverages, such as soft drinks and fruit juices, adds excessive simple sugar to the diet and is a major public health concern because of increased risk for overweight/obesity in childhood.^{43,44} A policy statement from the American Academy of Pediatrics recommends that children, aged 1 to 6 years, have less than 6 ounces of fruit juice per day.⁴⁵ Also, animal models with selective eating ate more when fed preferred, palatable foods, which indicates selective eating or food fussiness, may not only be a risk for underweight but also for obesity.²⁰

The CEBQ subscales of Enjoyment of Food and Food Responsiveness define the different appetite levels in young children as general and maladaptive. The regulation of appetite, an important determinant of eating behavior and weight, requires proper communication between the CNS and intestinal hormones; however, this interplay in FASD may have undergone alterations due to alcohol-related abnormalities interfering with the physiology of the central nervous system (CNS) and gastrointestinal tract.^{3,46,47} With a reduction of general appetite or food enjoyment, such as in boys and 5-year-olds with FASDs, food intake and weight may decrease. In fact, a recent study found poor appetite present in young children with prenatal alcohol exposure.¹³ It follows that, with maladaptive appetite levels cued by external sources, such as seen in the study children (boys, girls, and 4-year-olds), children may have a propensity to overeat, which would increase the risk of obesity.²⁰ Hence, if the dysregulation of appetite from higher Food

Responsiveness and Emotional Overeating is long-term, the consequences of the excessive food intake would include overweight/obesity.

From caregiver reports, atypical eating behaviors in children with FASDs, aged 3 to 5 years, were identified that can lead to clinically significant nutritional problems and weight issues. Since the eating problems vary, as does the many other alcohol-related deficits in FASD, there is a clear need for nutrition assessment, services, and interventions specifically tailored for FASD. The current study findings add to the existing literature by providing formative information to inspire further investigation into the atypical eating behaviors and the types of effective interventions to manage nutrition care in children with FASDs, aged 3 to 5 years.

Strength and Limitations

The study had limitations, which should be under consideration. This study was cross-sectional, which does allow for evidence of associations but not for identification of causality. More importantly, a major strength was that the study received responses from caregivers of children with FASDs, aged 3 to 5 years, across the United States and some internationally. Another limitation was that data were from purposive sampling and self-reported, subjective responses from caregivers, which are retrospective and may lead to under- or over-reporting due to social desirability. To lessen the effects of social desirability, caregivers were instructed their responses would be anonymous without any personal identifiers. Caregiver participation may also be limited because the survey was online but the snowball approach was used to increase the range of recruitment. At the same time, since the average age of FASD diagnosis is 9.5 years old (reported by the

Washington State FAS Diagnostic and Prevention Network), participation may not be representative of all preschoolers with FASDs because some children may have not yet been formally identified and diagnosed.⁴⁸ Yet, the study found that preschool-aged children with an FASD diagnosis were exhibiting a disruption of eating, indicating there is an early onset of atypical eating behaviors. In addition, the CEBQ subscales may not have captured all aspects of atypical eating behavior in the children with FASDs, aged 3 to 5 years, but, as an assessment tool, the CEBQ has been validated to identify eating behaviors in a variety of children. Notably, another major strength was that the study addressed a stage in child development in which the young child is transitioning into independent eating and a critical time for the provision of proper nutrition to brain for optimal development.

CONCLUSIONS

Atypical eating behaviors, consisting of maladaptive appetites, emotional overeating, selective eating, slower eating rates, and an increased need for drinks, were identified in children with FASDs, aged 3 to 5 years. In addition to the eating problems, there were indications of malnutrition in the higher prevalence of low birthweight and abnormal weight in preschool-aged children with FASDs. This is of major concern since nutritional inadequacies in young children with FASDs may further impair their growth and development, which is already compromised from the effects of prenatal alcohol exposure. Due to the study findings, early nutritional assessment, services, and interventions by registered dietitian nutritionists are important for children with FASDs to prevent possible nutrition deficits and improve the eating behavior.

Applications and implications for further research

The study findings aid in increasing the awareness of registered dietitian nutritionists about the nutrition and eating problems in FASD. With the identification of atypical eating behaviors, this supports the need for tailored nutrition intervention for children with FASDs and nutrition education for their caregivers.⁴⁹ Children with FASDs, who overeat because of emotional stress or external food cues, may require nutrition interventions helping them to express their emotions, instead of eating, and to respond to stress or environmental food intake stimulators by substituting a non-food activity, such as walking. Nutrition education can provide caregivers with nutrition information that encourages limiting fruit juice to 6 ounces per day and to make healthy choices for beverages, such as low-fat milk or water, to avoid sugar-sweetened drinks.⁵⁰ Also, nutrition education for caregivers can stress the importance of regularly scheduled meals and snacks fed in a pleasant setting with limited distractions, which may address the issues of lack of enjoyment in eating and maladaptive appetites.⁵¹ To improve food fussiness, nutrition counseling can suggest strategies to caregivers about offering new food frequently, along with foods favored by the children, or to blend in the non-preferred food with a preferred food to improve nutrition.^{51,52} Considering there are atypical eating behaviors present in FASD and reports of sensory sensitivities, future investigations may initially focus on the relationship of sensory processing disorders and selective eating behavior in children with FASDs.^{13,40}

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CHAPTER IV

EATING BEHAVIOR IN CHILDREN WITH FASDS IS RELATED DIFFERENTLY TO HIGHER LEVELS OF BEHAVIORAL PROBLEMS AND MEDICATION USE

ABSTRACT: Objective: To examine relationships between atypical eating behavior and global behavioral problems in children with fetal alcohol spectrum disorders (FASDs).

Methods: This research required respondents to be 18 years or older and the primary caretaker of at least one child with FASD (3 to 5 years). Fifty-four caregivers ($M_{age} = 42$ years, 98% female) completed online the Children's Eating Behavior Questionnaire (CEBQ) and Child Behavior Checklist 1.5-5 (CBCL/1.5-5) for 59 children ($M_{age} = 4$ years, 66% boys). Linear regression assessed relationships between the CEBQ subscales, the CBCL/1.5-5 scales, and medications. **Results:** The study children's highest CEBQ subscales scores were Slowness in Eating and Food Fussiness, with Emotional Overeating the lowest. Internalizing Problems, Externalizing Problems, and Total Problems (CBCL/1.5-5) were in the clinical range for many of the children with FASDs, (73%, 66%, and 76%, respectively). From caregiver reports, 83% of children had co-occurring diagnoses and 48% received medications. Regression analyses revealed:

Children ate faster if receiving more medications but ate slower with Somatic Complaints; Children with Internalizing Problems and Externalizing Problems exhibited more emotional eating. **Conclusions:** Results from caregiver reports suggest that children with FASDs have problems with a lack of interest in eating, emotional eating, and selective eating. It was found that the children may have more interest in eating if taking a greater number of medications, but less with somatic symptoms. In addition, depending on the type of behavioral problems, they may either emotionally under- or overeat. It appears the condition severity of FASD may underlie the children's atypical eating behaviors, which is related differently to higher levels of behavioral problems and medication use.

Introduction

Children with fetal alcohol spectrum disorders (FASDs) enter the preschool years with varying degrees of behavioral problems, developmental delays, and physical anomalies.¹⁻
⁴ These difficulties are the result of prenatal alcohol exposure and categorized under the term, FASD, which is the non-diagnostic designation for all alcohol-related birth defects.⁵ Depending on the extent of abnormalities, there is often the diagnosis of co-occurring disorders that require treatment with medications.⁶ Many of the behavioral problems, co-occurring diagnoses, and medications can adversely affect nutritional intake and place children with FASDs at higher risk for nutritional problems.⁷⁻¹⁰ Yet, little research has investigated eating behavior in children with FASDs, aged 3 to 5 years.

Since alcohol is a neurobehavioral toxin, children with prenatal alcohol exposure have structural and functional deficits of the central nervous system (CNS) leading to neuropsychological problems.¹ Because of the broad range of behavioral problems exhibited, co-occurring neurobehavioral disorders, such as attention deficit hyperactivity disorder (ADHD), autism spectrum disorder (ASD), reactive attachment disorder (RAD), and conduct disorder (CD), have been diagnosed in children with FASDs.⁴ There is evidence the co-occurring neurobehavioral diagnoses that occur with FASD can lead to nutrition and eating problems, such as in selective eating in children with ASD; indicating there is a comorbidity between atypical eating behaviors and global behavioral problems in children with FASDs.^{7,9}

In addition, malnutrition and difficulties in food consumption may be a concern in children with FASDs, who have somatic structural and functional impairment that disrupt

the intake, absorption, and metabolism of food.¹¹⁻¹³ Malnutrition may begin during infancy in infants with prenatal alcohol exposure who have increased oral sensitivity, poor suck, and failure to thrive.^{4,14} Alcohol-related birth defects include abnormalities in digestive function and facial structures, which can result in constipation, diarrhea, or mechanical problems limiting food intake.¹⁵

Since there is not a specific medication for FASD, children with FASDs receive medical management consisting of one or more medications in treatment of the co-occurring diagnoses.⁶ Medications, such as laxatives, psycho-stimulants, and antidepressants, have the potential for adverse nutrition-related effects, including decreased or increased appetite, impaired growth, and/or sleep disturbances.¹⁶ There may also be interactions between certain medications and foods.¹⁷ The Academy of Nutrition and Dietetics position paper on nutrition services for individuals with intellectual and developmental disabilities listed drug-nutrient interactions a concern in FASD, particularly medications affecting appetite.¹⁸

In sum, although eating problems can occur in children with typical development, children that have neurological, physical, or behavioral impairments, such as with FASD, are far more prone to have difficulty with eating from primary and/or secondary causes.¹⁸ Particularly, when eating problems persist during early childhood, there is a concern for inadequate dietary intake and malnutrition that can further impair brain development in children already neurologically compromised.¹⁹ Fuglestad et al. have substantiated that children with FASDs, aged 2 to 5 years, have poor diets lacking in fiber, omega-3 fatty acids, calcium, and vitamins D, E, and K.³⁵ Atypical eating behavior and associated

global behaviors in children with FASDs require identification for appropriate intervention to prevent nutritional issues.

Validated questionnaires are available to identify eating and global behavior problems in young children.^{20,21} Two behavioral instruments for preschool-aged children are the Children's Eating Behavior Questionnaire (CEBQ)²² and the Child Behavior Checklist 1.5-5 (CBCL/1.5-5).²³ The CEBQ and CBCL/1.5-5 have been employed successfully together in research investigating eating and behavioral problems in young children. For example, Velders et al.²⁴ evaluated the effects of the *FTO* minor allele at rs9939609 on eating behavior, BMI, emotions, and ADHD in preschoolers, while Mackenbach et al. investigated the relationship between BMI and emotional behavioral problems in early childhood.²⁵

The aim of this study was to explore the relationship between atypical eating behavior and global behavioral problems in children with FASDs, aged 3 to 5 years, through an online caregiver-reported survey. The *hypothesis* was that caregivers would report atypical eating behaviors in children with FASDs, aged 3 to 5 years, as assessed by the CEBQ, which would be positively associated with increased behavioral problems, as reported by the CBCL/1.5-5. If there is a positive association between instrumental scores of the CEBQ and CBCL/1.5-5 (high scores indicating disordered eating and high scores indicating disordered behaviors), this suggests that the condition severity of FASD may underlie the eating behavior problems. The age of the children was a key element in this study since this is a critical time for the developing brain to receive proper nutrition and spans the developmental stage when the child transitions to being an independent eater.^{26,27} Most importantly, identifying atypical eating associated with behavioral

problems will allow for development of condition specific nutrition clinical protocols for children with FASDs.

METHODS

The study was part of a larger research project, *Eating Behavior in Children with FASDs: A Mixed Methods Study*, which evaluated the eating behavior of children with FASDs, aged 3 to 5 years, through an online caregiver survey and focus groups of healthcare professionals.

A detailed description of the survey's design, recruitment, demographics, and response rate are in an earlier paper (pp. 48 - 50) that utilized the CEBQ to identify atypical eating behaviors in children with FASDs, aged 3 to 5 years.

Design and Participants

The present study assessed data from the caregivers of children with FASDs, aged 3 to 5 years, who responded to both the CEBQ and CBCL/1.5-5 in the study's online cross-sectional survey. Recruitment of caregivers extended across the United States and internationally. Caregivers qualified for the study if they were 18 years or older, acted as the primary caretaker, and cared for one or more children with FASDs between the ages of 3 to 5 years old. The study received approval from the Oklahoma State University Institutional Review Board.

The 54 caregivers, who qualified, were predominantly females (98%), ranging in age from 31 to 63 years old. Since five caregivers had two children with FASDs, there were questionnaire responses for 59 children. The children's mean age was 4.2 ± 0.8 years and

66% were boys. Since caregivers could leave out any question(s) while taking the survey, sample sizes per survey item vary from 34 (58%) to 59 (100%).

Measures

The survey for caregivers was placed online via *Qualtrics*© software (*Qualtrics*© 2015, Provo, UT) and included a socio-demographic questionnaire, the CEBQ, and the CBCL/1.5-5.

Socio-Demographic Questionnaire

The socio-demographic questionnaire captured information about the caregivers and children, such as gender and age. There were also questions regarding the children's co-occurring diagnoses and treatment with medication.

Co-occurring Diagnoses and Medications. The responses regarding the children's co-occurring diagnoses and medications were caregiver-reported and were not professionally confirmed or verified. Descriptions of the co-occurring diagnoses and medications were reported verbatim as submitted by the caregivers.

Children's Eating Behavior Questionnaire

The CEBQ was completed online by caregivers to assess different eating behaviors in preschool-aged children with FASDs.²³ The scoring of the 35 items (8 scales) in the CEBQ followed the 5-point Likert-type format [*never* (1), *rarely* (2), *sometimes* (3), *often* (4), and *always* (5)]. Prior rigorous testing has documented the internal validity and test-retest reliability of the CEBQ. Eating problems were indicated by subscales with higher scores.

To define eating behavior, the CEBQ categories used in the study were: Food Approach, which entails the subscales of Enjoyment of Food (desire to eat; EF, 4 items), Food Responsiveness (intake prompted by environmental cues; FR, 5 items), Desire to Drink (increased drinking, preferably sweetened with sugar; DD, 3 items) and Emotional Overeating (overeating due to negative events; EOE, 4 items); and Food Avoidance, which incorporates the subscales of Food Fussiness (avoidance of new and familiar foods; FF, 6 items), Slowness in Eating (eating slow due to lack of interest in eating; SE, 4 items), Satiety Responsiveness (decreasing food intake after eating; SR, 5 items), and Emotional Undereating (eating less because of negative events; EUE, 4 items).²³ Overall, the Food Approach subscales (EF, FR, DD, and EOE) indicate overweight/obesity proclivity, while Food Avoidance subscales (FF, SE, SR, and EUE) indicate underweight tendencies.

The following are examples of CEBQ items: *My child is interested in food* (EF), *If given the chance, my child would always have food in his/her mouth* (FR), *If given the chance, my child would drink continuously throughout the day* (DD), *My child eats more when s/he has nothing else to do* (EOE), *My child is difficult to please with meals* (FF), *My child eats more and more slowly during the course of a meal* (SE), *My child cannot eat a meal if s/he has had a snack just before* (SR), and *My child eats less when s/he is tired* (EUE).²³ Items reverse coded in the questionnaire were: *My child is interested in tasting food s/he hasn't tasted before* (FF), *My child enjoys a wide variety of foods* (FF), *My child enjoys tasting new foods* (FF), *My child finishes his/her meal quickly* (SE) and *My child has a big appetite* (SR).

As a measure of internal reliability, Cronbach's alpha ranged from 0.77 to 0.95 for the CEBQ subscales in this study, which were comparable to the Cronbach's alpha determined in the development of the CEBQ that ranged from 0.74 to 0.91.²³ As reported in the previous paper (p. 52), the Principal Component Analysis of the CEBQ items and correlations between subscales showed appropriate clustering and factor structure with similar loading of Slowness in Eating and Satiety Responsiveness,.

Child Behavior Checklist 1.5-5

In this study, the primary caregivers responded to the CBCL/1.5-5 in the online survey to describe the children's general behaviors that had occurred within the last two months. Responses to the 99 questions in the CBCL/1.5-5 provided a standardized description of global behavioral functioning in children with FASDs and determined what behaviors were above a normal level.²⁴ Through ASEBA© computer software, responses were tabulated into the Total Raw Scores, *T* scores, and percentiles of the syndrome, broadband, and the Diagnostic and Statistical Manual of Mental Disorders (DSM)-oriented scales (based on the DSM-IV).

Syndrome scales of the CBCL/1.5-5 reflect patterns of persistent abnormal behaviors in the child, defined as Emotionally Reactive (distracted over changes), Withdrawn (introverted), Anxious/depressed (nervous and sad), Somatic Complaints (physical manifestations), Sleep Problems (nightmares, disrupted sleep), Attention Problems (poor concentration, inability to focus) and Aggressive Behavior (obstinate, noncompliant).²⁴ Based on the syndrome scales, the CBCL/1.5.5 has the broad categories of Internalizing Problems (excessive control of actions and feelings; syndrome scales of Emotionally Reactive, Withdrawn, Anxious/depressed, and Somatic Complaints) and Externalizing

Problems (limited control of actions and feelings; syndrome scales of Attention Problems and Aggressive Behavior); however, the calculation of the broad categories excludes the Sleep Problems scale. Internalizing Problems and Externalizing Problems, when combined, represent a general measure of global behavior, designated as Total Problems.

Since the syndrome scales correlate with DSM-IV, the DSM-oriented scales provide convergent validity data that defines certain mental health diagnoses.²⁴ The DSM-oriented scales represent symptoms of DSM diagnoses, categorized as Stress Problems, Depressive or Affective Problems, Anxiety Problems, Autism Spectrum or Pervasive Developmental Problems, Attention deficit/hyperactivity Problems, and Oppositional Defiant Problems. Since this study was evaluating behavioral problems and not identifying mental health disorders, the DSM-oriented scales were not included in CEBQ comparisons.

Scoring of questions in the CBCL/1.5-5 follows a 3-point Likert scale [‘not true’ (0), ‘sometimes true’ (1), or ‘very true’ (2)]. The Total Raw scores of the scales convert to *T* scores ($M = 50$, $SD = 10$), which indicate a measure of clinical functioning.²⁴ Examples of items in the CBCL/1.5-5 include *disturbed by any change in routine*, *overeating*, *stomach aches or cramps*, and *afraid to try new things*. Higher scale scores reflect a higher degree of behavior problems in the children. For the *T*-scores of the syndrome scales and DSM-oriented scales, cut-offs range as: Normal (N) is <65, borderline clinical (B) is ≥ 65 to <70, and clinical (C) is ≥ 70 (comparable to $\geq 98^{\text{th}}$ percentile of the normative sample). The *T*-scores of Internalizing, Externalizing, and Total Problems range as: N <60, B ≥ 60 to <64, and C ≥ 64 ($\geq 90^{\text{th}}$ percentile). Scales of the CBCL/1.5-5 were based on the rating of 1,728 children and normed on a US sample of 700

children.²⁴

Cronbach's alphas were 0.65 to 0.96 for the study's CBCL/1.5-5 scales and were within acceptable range. The study's reliability statistics were comparable to the CBCL/1.5-5 reference coefficients from Achenbach and Rescorla (2000) [0.66 to 0.95].²⁴ Since the DSM-oriented scales represent criteria, Cronbach's alphas were not determined. Dr. Maureen Sullivan, Associate Professor in the Department of Psychology, supervised the use and interpretation of this questionnaire due to her expertise with the instrument. This support was necessary to obtain permission from the publishers to use the instrument.

Statistical Analysis

The *IBM SPSS Version 21.0 software for Windows* (SPSS, Inc, Chicago, IL) was used to analyze the data. Analysis was conducted on all children and then repeated after randomly selecting 5 children from the 10 children of the caregivers ($n = 5$) with two children. Due to the study being exploratory and the two groups being similar, all children with FASDs (child 1 and child 2), aged 3 to 5 years, of the caregivers were considered as one independent group in the study. The dichotomous variables in the survey were designated as: (1) yes, (2) no and (1) male/boy, (2) female/girl. Data consisted of interval, nominal, ordinal, and Likert-type scales. The Total Raw Scores of the CEBQ items were grouped per subscale and also combined into the Food Approach and Food Avoidance categories. The Total Raw Scores, percentiles, and *T* scores of the CBCL/1.5 -5 scales were calculated by ASEBA© Technical Support Department. Analysis included descriptive statistics of the socio-demographic characteristics of the caregivers and children, the CEBQ subscales, and CBCL/1.5-5 scales. Statistical testing of the CEBQ scores and CBCL/1.5-5 total raw scores consisted of Pearson's product-

moment correlations, cross tabulations, independent samples *t*-tests, and one-way ANOVA. Tukey adjustments were performed for post hoc pairwise comparisons when indicated.

To test study hypotheses, two multiple linear regression models were used. Multiple linear regression model 1 was entered with backward elimination and consisted of one CEBQ subscale, as the dependent variable, and the predictors of total number of children's medications and the CBCL/1.5-5 scales of Internalizing Problems, Externalizing Problems, and Sleep Problems. Medication was selected due to the adverse side effects related to eating and was determined to not have correlations with the CBCL/1.5 scales. Internalizing Problems and Externalizing Problems (broad scales) were chosen, representing the strongest scales of the CBCL/1.5-5; while, Sleep Problems (syndrome scale) was used due to its exclusion from the two broad scales. If the CBCL/1.5-5 broad scales were not significant predictors of a CEBQ subscale, multiple linear regression model 2 was used with backward elimination and consisted of the CEBQ subscale, its correlated CBCL/1.5-5 syndrome scale, and total number of children's medications. All regression models were checked for violations of the linear, normality, multi-collinearity, auto-correlation, and homoscedasticity assumptions.

During analysis, outliers were not excluded and missing data were omitted. Results, including post hoc comparisons (Tukey) were considered statistically significant at $p < 0.05$ (two-tailed). The effect sizes for Pearson's product-moment correlations were determined using Cohen's conventions as small (0.1 – 0.3), medium (0.3 – 0.5), and large (0.5 – 1.0).²⁹ Cohen's conventions for R^2 were small (0.02), medium (0.15), and large (0.26) for effect sizes in multiple linear regression. Since the study was exploratory and

the relationship of eating and global behavioral problems with FASD has not had prior evaluation, the number of analyses erred on the side of minimizing the type II error and was not controlled for familywise error.

RESULTS

Characteristics of Sample

Table 1 presents the socio-demographic characteristics of the study sample. Caregivers resided in the Northeast (n = 6, 12%), Midwest (n = 14, 29%), Western (n = 13, 26%), and Southern (n = 14, 29%) regions of the United States and 4% (n = 2) internationally. Most of the caregivers were adoptive or foster parents to the 59 children (n = 49, 83%).

Table 1. Socio-demographic characteristics of caregiver and children with FASDs, aged 3 to 5 years

| Caregiver Characteristics | <i>M±SD^a</i> | <i>n</i> | Percentages |
|--|--------------------------------|-----------------|--------------------|
| Age (yrs) | 42.3±8.1 | 45 | |
| Gender | | | |
| Female | | 50 | 98.0 |
| Male | | 1 | 2.0 |
| Total | | 51 | 100.0 |
| Children Characteristics | <i>M±SD^a</i> | <i>n</i> | Percentages |
| Age (yrs) | 4.2±0.8 | 59 | |
| Gender | | | |
| Girls | | 20 | 34.0 |
| Boys | | 39 | 66.0 |
| Total | | 59 | 100.0 |
| Co-occurring Diagnoses | | | |
| Yes | | 48 | 83.0 |
| Number of Co-occurring Diagnoses per Child | 2.8±2.3 | | |
| No | | 10 | 17.0 |
| Total | | 58 | 100.0 |
| Medications | | | |
| Yes | | 28 | 48.0 |
| Number of Medications per Child | 2.4±1.7 | | |
| No | | 30 | 52.0 |
| Total | | 58 | 100.0 |

^a *M±SD* = Mean plus or minus Standard deviation.

Table 2 lists the co-occurring diagnoses as reported by the caregivers. Many of the 59 children with FASDs (n = 48, 83%) had at least one co-occurring diagnoses. There were

3% (n = 2) of the children reported with fetal alcohol syndrome (FAS). Roughly, 27% of the total number of co-occurring diagnoses were related to psychiatric disorders, such as ADHD (n = 18) and ASD (n = 5), and 14% related to nutrition problems, such as complaints of acid reflux (n = 3) and chronic constipation (n = 2). Due to half of the children (n = 29, 50%) having two or more co-occurring diagnoses, the descriptions of co-occurring diagnoses and percentages by groups are based on the total number of co-occurring diagnoses.

Table 2. Total and percentages of co-occurring diagnoses in children with FASDs, aged 3 to 5 years, as reported by caregivers

| Co-occurring Diagnoses^a | n | Percentages |
|---|----------|--------------------|
| Total Number of Co-occurring Diagnoses | 136 | 100.0 |
| Physical Anomalies | 8 | 5.9 |
| Hypospadias | | |
| Growth Issues | | |
| Failure To Thrive | | |
| Acrocyanosis | | |
| Enlarged Adenoids | | |
| Frail Body | | |
| Hypermobility | | |
| Organ System Dysfunction | 21 | 15.4 |
| Gastrointestinal | | |
| Delayed Gastric Emptying | | |
| Acid Reflux | | |
| Feeding Issues | | |
| Chronic Constipation | | |
| G-Tube | | |
| Gluten Issues | | |
| Necrotizing Enterocolitis | | |
| Cardiac | | |
| Pre-Ventricular Contraction | | |
| Premature Junction Beat | | |
| Skin | | |
| Hypohydrotic Ectodermal Dysplasia | | |
| Eczema | | |
| Pulmonary | | |
| Bronchopulmonary Dysplasia | | |
| Renal | | |
| Single Kidney | | |
| Hepatic | | |
| Liver Issues | | |
| Psychiatric Disorders | 36 | 26.5 |
| Attention Deficit Hyperactivity Disorder (n = 18) | | |
| Autism Spectrum Disorder (n = 5) | | |
| Reactive Attachment Disorder (n = 5) | | |
| Posttraumatic Stress Disorder | | |

| | | |
|--------------------------------------|----|------|
| Oppositional Defiant Disorder | | |
| Bipolar Disorder | | |
| Hyperkinetic | | |
| Impulsive | | |
| Pica | | |
| Low IQ | | |
| Sensory | 20 | 14.7 |
| Vision Impairment | | |
| Septo-optic dysplasia | | |
| Sensory Processing Disorder (n = 13) | | |
| Auditory Processing Deficits | | |
| Visual Processing Deficits | | |
| Speech Sound Disorder | | |
| Neurological Disorders | 15 | 11.0 |
| Cerebral Palsy | | |
| Microcephaly | | |
| Abnormal EEG | | |
| Cognitive Processing Deficits | | |
| Encephalopathy | | |
| Organic Brain Damage | | |
| Neurohypophysis | | |
| Ataxia ^b | | |
| Partial Complex Seizures | | |
| Dyspraxia | | |
| Verbal Apraxia | | |
| Oral Motor Dyspraxia | | |
| Dysarthritic | | |
| Developmental | 9 | 6.6 |
| General Delays | | |
| Major Speech/Language Delay | | |
| Social Emotional Delay | | |
| Learning Disabled | | |
| Allergies | 7 | 5.1 |
| Asthma | | |
| Food Allergies | | |
| Milk Intolerance | | |
| Motor | 3 | 2.2 |
| Ptosis of Left Eye | | |
| Low Motor Tone | | |
| Motor Apraxia | | |
| Dyspraxia | | |
| Other | 17 | 12.5 |
| Lack of Coordination | | |
| Mood Disorder (non-specified) | | |
| Childhood trauma/abuse | | |

Anxiety (non-specified)
Explosive Personality
Processing Disorder
Fetal Depakote Syndrome
Prenatal Cocaine Exposure
Klippel Feil Syndrome
Sprengel's Deformity
Sleep Disturbance
Sleep Apnea
Ear Infections
Hip Problems
Webbed Neck
Genetic Syndrome

^aCo-occurring diagnoses were often greater than 1 per child and reported verbatim by caregivers. Some may not be specifically defined in the DSM-IV, which the CBCL/1.5-5 is based on, and were not professionally confirmed. Frequency for each type of diagnosis is not listed due to many diagnoses being only reported once.

Recorded in Table 3 are the medications the children were receiving as reported by the caregivers, along with a listing of associated adverse nutrition side effects. Almost half of the children ($n = 28$, 48%) received medications with 24% ($n = 14$) on two or more medications. Since many of the children were taking more than one medication, the types and percentages of the medications were based on the total number of medications. Of the total number of medications, 56% of the medications were psychiatric medications with 18% ($n = 5$) of children on methylphenidate and 14% ($n = 4$) on risperidone. All of the children's medications had nutrition-related side effects and 10% ($n = 7$) of the medications treated gastrointestinal problems.^{6, 16} Pearson's product-moment correlations found a significant positive linear association between the total number of co-occurring diagnoses and the total number of medications in the children ($r = 0.344$, $p = 0.008$, $n = 58$). Interestingly, children without reported co-occurring diagnoses were not receiving any medications.

Table 3. Total, percentages, and associated nutrient-related side effects of medications in children with FASDs, aged 3 to 5 years, as reported by caregivers

| Medications^a | <i>n</i> | Percentage | Nutrition-related Side Effects^{bc} |
|--|-----------------|-------------------|---|
| Total Number of Medications | 66 | 100 | |
| Psychiatric | 37 | 56.0 | |
| Aripiprazole | | | Increased Weight/Obesity Increased or decreased salivation Dry Mouth Nausea/Vomiting Dyspepsia/Abdominal pain Constipation or Diarrhea |
| Atomoxetine HCl | | | Decreased appetite/Decreased weight Delayed Growth in Children Dry Mouth Nausea/Vomiting Dyspepsia/Abdominal pain Constipation or Diarrhea |
| Clonidine | | | Increased Weight due to edema Anorexia Dry Mouth Nausea/Vomiting Constipation |
| Detromethylphenidate | | | Decreased Growth with Long Term Use |
| Dextroamphetamine Sulf-Saccharate/Amphetamine Sulf-Aspartate | | | Dry Throat |
| Fluoxetine | | | Nausea Anorexia Abdominal Pain |
| Guanfacine | | | Increased Weight Due to Edema Anorexia Dry Mouth Nausea/Vomiting Constipation |
| Imipramine | | | Weight gain or loss |
| Lamotrigine | | | Anorexia/Decreased weight Nausea/Vomiting Dyspepsia/Abdominal pain Constipation or Diarrhea |
| Lisdexamfetamine | | | Decreased weight |
| Methylphenidate Slow Release | | | Anorexia |
| Oxcarbazepine | | | Hyponatremia |
| Risperidone | | | Increased appetite |
| Sertraline | | | Decreased appetite |
| Trazodone hydrochloride | | | Taste Changes Dyspepsia Nausea/Vomiting Constipation or Diarrhea Increased appetite/Increased or decreased weight Dry Mouth |
| Asthma/Allergies | 13 | 20.0 | |
| Albuterol Sulfate Nebulizer | | | Peculiar Taste Dyspepsia |

| | | | |
|-------------------------------------|---|------|---|
| Cetirizine | | | Diarrhea |
| Cyproheptadine | | | Increased Appetite or Anorexia |
| Fluticasone Furoate | | | Nausea/Vomiting |
| Loratadine | | | Increase weight |
| | | | Increased appetite |
| | | | Dry Mouth |
| | | | Nausea/Vomiting |
| | | | Constipation or Diarrhea |
| | | | Increased thirst |
| Mometasone | | | Decreased sense of taste |
| | | | Nausea/Vomiting |
| Montelukast Sodium | | | Dyspepsia |
| Gastrointestinal Medications | 7 | 10.0 | |
| Fiber Supplements | | | Vomiting |
| | | | Diarrhea/Cramping |
| | | | Dry Mouth |
| Hydroxyzine | | | Decrease absorption of Iron and vitamin B12 |
| Omeprazole Magnesium | | | Nausea |
| | | | Abdominal Pain |
| | | | Diarrhea |
| Ondansetron | | | Bitter Taste |
| | | | Nausea |
| | | | Abdominal Pain |
| | | | Constipation or Diarrhea |
| Polyethylene Glycol | | | Nausea |
| Other | 3 | 5.0 | |
| Pimecrolimus Cream | | | Fever, Chills |
| Antibiotics | | | Nausea/Vomiting |
| | | | Diarrhea |
| Nutrition Supplements | 6 | 9.0 | |
| Melatonin | | | Abdominal Discomfort |
| Multivitamins | | | Nausea |
| Ferrous Sulfate | | | Constipation |
| Fish Oil | | | Abdominal Pain/Belching |

^aSome medications are used in treatment of other conditions. Some children received more than one medication. The medications were reported verbatim by the caregivers and not professionally confirmed. Frequency of individual medications was not listed since some medications were only given to one child.

^bOzsfarati J, Koren G. Medications used in the treatment of disruptive behavior in children with FASD--a guide. *J Popul Ther Clin Pharmacol*. 2015;22(1):e59-67.

^cPronsky ZM. *Food-Medication Interactions*TM 14th ed. Birchrunville, PA: Food-Medication InteractionsTM; 2006.

Children's Eating Behavior Questionnaire

Descriptive statistics and Cronbach's alpha of the CEBQ subscales are in Table 4. The *mean* scores of the CEBQ subscales ranged from 2.1±1.0 to 3.5±1.2. The CEBQ subscale

with the highest score was Slowness in Eating, followed by Food Fussiness. The subscale with lowest score was Emotional Overeating.

Table 4. Descriptive statistics and Cronbach's α of CEBQ subscales for children with FASDs, aged 3 to 5 years, as reported by caregivers

| CEBQ Subscale | Cronbach's α | $M \pm SD^a$ | n |
|------------------------|---------------------|---------------|-----|
| Food Approach | | 2.8 \pm 0.9 | 54 |
| Enjoyment of Food | 0.91 | 3.0 \pm 1.1 | 57 |
| Food Responsiveness | 0.80 | 2.7 \pm 1.3 | 56 |
| Desire to Drink | 0.89 | 3.4 \pm 1.3 | 57 |
| Emotional Overeating | 0.79 | 2.1 \pm 1.0 | 56 |
| Food Avoidance | | 3.4 \pm 0.8 | 47 |
| Food Fussiness | 0.91 | 3.5 \pm 1.1 | 56 |
| Slowness in Eating | 0.74 | 3.5 \pm 1.2 | 55 |
| Satiety Responsiveness | 0.74 | 3.3 \pm 1.1 | 57 |
| Emotional Undereating | 0.74 | 3.1 \pm 1.0 | 53 |

^a $M \pm SD$ = Mean plus or minus Standard deviation.

Child Behavior Checklist 1.5-5

Results for the CBCL/1.5-5 descriptive values and percentages of children in the clinical range are in Table 5. The Total Problems *mean T* score was the highest score and in the clinical range for 76% of the study children. The *mean T* scores of Internalizing Problems and Externalizing Problems were in the clinical range for 73% and 66% of the children, respectively. In the syndrome scales, the *mean T* score for Emotionally Reactive was in the clinical range, while five of the six remaining syndrome scales were in the borderline range. For the DSM-oriented scales, the following scales had *mean T* scores in the clinical range: Stress Problems, Depressive Problems, Anxiety Problems, and Autism

Spectrum Problems. Of the DSM-oriented scales, Autism Spectrum Problems had the highest percentage of children (68%) in the clinical range.

Table 5. Descriptive statistics for CBCL/1.5-5 Total Raw Scores, *T* Scores, and clinical range for syndrome, broad scales and DSM-oriented scales in children with FASDs, aged 3 to 5 years, as reported by caregivers

| Scales | Cronbach's α | Total Raw Scores | | Range | Percentage of Clinical Ranges for All Children based on mean <i>T</i> scores ^e | |
|--|---------------------|------------------|--------------|----------------|---|------------------|
| | | $M \pm SD^a$ | $M \pm SD^a$ | | Borderline %(n) | Clinical %(n) |
| Syndrome Scales | | | | | | |
| Emotionally Reactive | 0.76 | 8.32±4.5 | 70.05±12.8 | C ^d | 23.7(14) | 47.5(28) |
| Anxious Depressed | 0.74 | 6.39±3.5 | 64.10±10.6 | N ^b | 25.4(15) | 27.1(16) |
| Somatic Complaints | 0.65 | 5.92±3.4 | 65.92±9.1 | B ^c | 27.1(16) | 37.3(22) |
| Withdrawn | 0.78 | 5.92±3.3 | 69.20±10.5 | B ^c | 13.6(8) | 52.5(31) |
| Sleep Problems | 0.78 | 6.42±3.7 | 65.12±13.2 | B ^c | 6.8(4) | 32.2(19) |
| Attention Problems | 0.78 | 6.85±2.7 | 69.31±9.1 | B ^c | 5.1(3) | 67.8(40) |
| Aggressive Problems | 0.94 | 21.02±9.5 | 67.86±13.5 | B ^c | 18.6(11) | 42.4(25) |
| Broadband Scales | | | | | | |
| Internalizing Problems | 0.82 | 26.54±11.4 | 69.32±10.2 | C ^d | 10.2(6) | 72.9(43) |
| Externalizing Problems | 0.94 | 27.86±11.4 | 67.83±14.2 | C ^d | 8.5(5) | 66.1(39) |
| Total Problems | 0.96 | 85.32±32.7 | 71.69±12.8 | C ^d | 11.9(7) | 76.3(45) |
| DSM^f-oriented Scales | | | | | | |
| | | 6.10±2.7 | 70.31±10.6 | C ^d | 10.2(6) | 61.0(36) |

| | | | | | |
|--|----------|------------|----------------|---------|----------|
| Stress Problems | | | | | |
| Depressive Problems | 8.03±4.1 | 71.17±10.9 | C ^d | 5.1(3) | 61.0(36) |
| Anxiety Problems | 9.42±4.2 | 70.49±12.4 | C ^d | 3.4(2) | 62.7(37) |
| Autism Spectrum Problems | 9.03±4.6 | 70.52±11.0 | C ^d | 13.6(8) | 67.8(40) |
| Attention Deficit Hyperactivity Problems | 9.14±3.0 | 65.78±8.1 | B ^c | 6.8(4) | 42.4(25) |
| Oppositional Defiant Problems | 6.66±3.8 | 63.56±10.7 | N ^b | 0(0) | 37.3(22) |

^a $M \pm SD$ = Mean plus or minus Standard deviation.

^bN = Normal range.

^cB = Borderline clinical range.

^dC = Clinical range.

^ePercentage of children in the normal range for each scale is determined by $100 - (\text{Borderline} + \text{Clinical range})$.

^fDSM = Diagnostic and Statistical Manual.

Associations between the CEBQ and CBCL/1.5-5

Several significant bivariate correlations with medium effect sizes were noted between the CEBQ subscale scores and CBCL/1.5-5 total raw scores of the study children. Of the CEBQ scales, there was more Satiety Responsiveness ($r = 0.318, p = 0.016, n = 57$), Slowness in Eating ($r = 0.278, p = 0.040, n = 55$), and Food Avoidance ($r = 0.314, p = 0.031, n = 47$) with less Enjoyment of Food ($r = -0.333, p = 0.011, n = 57$) in association with children who experienced higher levels of Somatic Complaints (CBCL/1.5-5). If under stress, there was more Emotional Overeating (CEBQ) in children who had higher scores in the CBCL/1.5-5 syndrome scales of Aggressive Behaviors ($r = 0.366, p = 0.006, n = 56$) and Externalizing Problems ($r = 0.339, p = 0.011, n = 56$); while, more Emotional Undereating (CEBQ) was associated with higher scores in the Anxious Depressed Problems ($r = 0.305, p = 0.026, n = 53$), Internalizing Problems ($r = 0.295, p = 0.032, n = 53$), and Total Problems ($r = 0.289, p = 0.036, n = 53$) of the CBCL/1.5-5. In addition, there was more Food Fussiness (CEBQ) in children with higher levels of Sleep Problems ($r = 0.301, p = 0.024, n = 56$) and Internalizing Problems ($r = 0.284, p = 0.034, n = 56$) [CBCL/1.5-5 scales]. There were no significant correlations between Food Responsiveness, Food Approach, and Desire to Drink subscales (CEBQ) and the CBCL/1.5-5 syndrome scales.

Differences of the CEBQ and CBCL/1.5-5 by Co-occurring Diagnoses and Medications

Co-occurring Diagnoses

Independent samples *t*-tests were not significantly different in the eight subscales of the CEBQ by presence or absence of co-occurring diagnoses but differences were noted with the CBCL/1.5-5. In the CBCL/1.5-5 scales (Total Raw Scores), independent samples *t*-tests between children with and without co-occurring diagnoses found that the children with co-occurring diagnoses had a statistically significant difference in Somatic Complaints ($M = 6.42, SD = 3.3; M = 4.00, SD = 3.2; t(56) = 2.117, p = 0.039$), Internalizing Problems ($M = 28.40, SD = 10.6; M = 19.80, SD = 13.89; t(56) = 2.204, p = 0.032$), and Total Problems ($M = 90.29, SD = 28.9; M = 67.20, SD = 40.8; t(56) = 2.136, p = 0.037$). Otherwise, there were no significant differences in the remaining CBCL/1.5-5 scales and children with or without co-occurring diagnoses.

Medications

Independent samples *t*-tests [scoring: (1) yes, (2) no] between the CEBQ subscales and presence of medication found that children taking medications ($M = 3.64, SD = 1.03$) had a lower appetite (CEBQ: Higher Satiety Responsiveness) compared to children not taking medicines [$M = 2.98, SD = 0.86; t(55) = 2.651, p = 0.010$]. Evaluating by the number of medications per child (no, one, and two or more medications taken by the child), one-way ANOVA demonstrated significant differences in the CEBQ subscales of Satiety Responsiveness, Slowness in Eating, and Food Avoidance. After post hoc comparisons (Tukey), children, who received one medication, had significantly higher Satiety Responsiveness (decreased appetite) than children not on medication [$F(2,54) = 5.097, p = 0.009$] but no difference was seen in the children taking two or more medications. Whereas, with Slowness in Eating [$F(2,54) = 7.055, p = 0.002$], children not taking medications had lower Slowness in Eating than children who received two or more

medications, along with the children taking one medication lower than the children on two or more medication group, reflecting a faster eating rate in children taking more medications. In Food Avoidance [$F(2,44) = 3.252, p = 0.048$], children receiving one medication had more of a tendency towards inhibited eating in comparison to children not taking medication. There were no other significant differences between the number of medications per child and the CEBQ subscales or with the CBCL/1.5-5 scales total raw scores.

Multivariate Associations between CEBQ and CBCL/1.5-5

Regression models are displayed in Table 6. Using model 1, the multiple linear regression analyses revealed there was more Emotional Undereating and Food Fussiness expressed in children who had a higher level of Internalizing Problems; while, on the other end of the spectrum, there was more Emotional Overeating in children with higher levels of Externalizing Problems. Since the broad scales were not significant predictors of Slowness in Eating, the second linear regression model of Slowness in Eating, number of children's medications, and Somatic Complaints, had a large effect size ($R^2 = 0.271$). In this model, Slowness in Eating was lower in children who received more medications but was higher in the presence of higher Somatic Complaints. Regression analyses for Enjoyment of Food, Satiety Responsiveness, Food Responsiveness, Desire to Drink, Food Approach, and Food Avoidance (CEBQ) were non-significant.

Table 6. Multiple linear regression models with backward elimination between the CEBQ subscales, CBCL/1.5-5 scales, and total number of medications in children with FASDs, aged 3 to 5 years

| Dependent Variables | | Independent Variables | | | | | |
|-----------------------|----------|--------------------------------------|----------|--------------------------------------|----------|--|----------|
| | | Internalizing Problems ^{ac} | | Externalizing Problems ^{ac} | | Medications and Somatic Complaints ^{bc} | |
| CEBQ Subscales | <i>n</i> | <i>R</i> ² | <i>p</i> | <i>R</i> ² | <i>p</i> | <i>R</i> ² | <i>p</i> |
| Slowness in Eating | 55 | | | | | 0.271 | 0.000 |
| Food Fussiness | 56 | 0.081 | 0.034 | | | | |
| Emotional Undereating | 53 | 0.087 | 0.032 | | | | |
| Emotional Overeating | 56 | | | 0.115 | 0.011 | | |

^aMultiple linear regression with model 1.

^bMultiple linear regression with model 2.

^cMultiple linear regression criteria for probability of *F*: Entry of 0.05 and removal of 0.10.

Discussion

To our knowledge, this is the first research investigating the association between atypical eating behaviors and global behavioral problems in children with FASDs, aged 3 to 5 years. The findings strongly suggest that preschool-aged children with FASDs have atypical eating behaviors in association with higher levels of behavioral problems and medications. This relationship was found to be complex depending on the specific eating problem, the type of global behavior, and the number of medications.

The most common eating problem in the children with FASDs was Slowness in Eating (CEBQ), which represents the rate of, or interest, in eating.²³ Notably, study findings revealed that the rate of eating was lower when children experienced somatic symptoms but was faster for children taking medications. This may be explained by the presence of somatic symptoms noted in the children that can decrease eating, such as acid reflux, delayed gastric emptying, and chronic constipation; while, on the other hand, medications taken by the children, such as risperidone, may increase appetite or eating. As evidence, a similar relationship between eating problems and somatic symptoms has been noted by Kerwin et al., in which an association was found between poor eating and gastrointestinal complaints of vomiting and irregular bowel habits in children with pervasive developmental disorders.³⁰ In support of medications affecting eating, a study by Martin et al. (2000) found increased appetite and weight gain in 78% of children and adolescents, who received risperidone, while undergoing inpatient psychiatric care for behavioral disorders.³¹ Secondly, the treatment of the somatic complaints, such as taking fiber for constipation, acts to reduce the severity of symptoms and, ultimately, would

improve eating. Overall, it appears the eating behavior in children with FASDs may be detrimentally influenced by somatic problems but likely ameliorated by medication.

The second most commonly reported eating behavior in the study children was Food Fussiness or selective eating, which refers to children that eat slowly, have smaller meals, and exhibit strong food preferences.²³ Recent nutrition research has identified selective eating as a eating behavior problem in children with FASDs, aged 4 to 15 years.³² Study results show that children with FASDs, who had increased internalizing behaviors, were more selective in their eating and that Food Fussiness or selective eating also had a strong correlation with sleep disturbances. In a similar manner, a study by McDermott et al. found that children with typical development, aged 2 to 4 years, had a selective or irregular eating pattern associated with co-occurring physical problems, anxious/depressed behaviors, and lack of adequate sleep.³³ It would seem that selective eating in children with FASDs may be related to higher levels of internalizing behaviors, such as in sleep disturbances, anxiousness and depression.

Covering both extremes of food intake and behavior spectrums, data analyses indicated that the children with FASDs, who had internalizing behavioral problems, ate less in association with emotional stress; whereas, children with FASDs, who had externalizing behavioral problems, ate more under emotional stress. Emotional under- and overeating in FASD have yet to be fully been investigated. However, Micali et al. demonstrated in children with typical development, aged 5 to 7 years, there was an association between emotional undereating, physiological complaints, and emotional problems of anxiety and depression.³⁴ As part of the Generation R study, Mackenbach et al. also found, that children, who had internalizing behavioral problems, aged 3 to 4 years, exhibited more

emotional undereating and had a reduced body mass index (BMI).²⁶ With regards to emotional overeating, Anderson et al. followed a cohort of children with typical development from 2 to 12 years old and demonstrated externalizing behaviors of hyperactivity, aggression, and attention problems were related to increased weight gain.³⁵ Khalife et al. also identified an increased risk of obesity in children with ADHD and proposed that the increased weight gain may be the result of overeating when stressed.⁹ The findings imply that preschool-aged children with FASDs have differences in behavioral problems, that, when stressed, could lead to either underweight or overweight/obesity.

It appears that children with FASDs may be at increased risk of malnutrition and eating problems, in relation to the severity of global behavioral problems and susceptibility to the adverse medication side effects. This indicates that there is an important need for identification of atypical eating behavior in preschool-aged children with FASDs in order to provide early and effective nutrition intervention.

Strength and Limitations

One of the major limitations in the study was the small sample size; however, recruitment spanned across the United States and internationally. Another consideration was that caregiver responses were subjective and may be biased by a need for social desirability. To reduce this bias, participants were instructed their responses were anonymous without links to personal identifiers. In addition, caregiver responses regarding co-occurring diagnoses and medications were not professionally confirmed. Also, some co-occurring diagnoses of the children reported by the caregivers, such as

‘explosive personality’, were unusual for this age range and not technically consistent with the DSM-IV, in which the CBCL/1.5-5 is based on. Others, such as attention deficit hyperactivity disorder (ADHD) and learning disabilities, may be difficult to diagnose under the age of 6 years. However, since the caregivers reported a co-occurring diagnosis, this suggests concerns regarding the children’s health and was considered meaningful to this exploratory study. Since the survey was administered online, caregivers without computer skills may have been unable to respond but the snowballing approach was used to encourage inclusion of all types of caregivers. As expected, the respondents in this study were primarily female but males were not excluded from participation.

Conclusions

Eating behavior in FASD appears to follow the same complex and varied path as the other diverse problems that occur in children with prenatal alcohol exposure. The findings suggest there is a complex relationship between atypical eating behavior and global behavioral problems in children with FASDs, aged 3 to 5 years, in which the severity of FASD problems may underlie the eating behavior problems. Assessment of preschool-aged children with FASDs should include identification of eating behaviors, associated behavioral problems or co-occurring diagnoses, and medication side effects to allow for the provision of effective nutrition intervention, education, and services.

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CHAPTER V

ATYPICAL EATING BEHAVIOR IDENTIFIED IN CHILDREN WITH FASDS AS REPORTED BY HEALTHCARE PROFESSIONALS IN FOCUS GROUPS

ABSTRACT

Background: Children with fetal alcohol spectrum disorders (FASDs) experience compromised physical, mental, and behavioral health from prenatal alcohol exposure and are at risk for malnutrition and disordered eating. Yet, few studies have expressly investigated nutrition and eating behaviors in children with FASDs. **Aims:** The study's specific aim was to explore, through healthcare professionals' perspectives, the eating behavior of preschool-aged children with FASDs. **Methods:** This research consisted of in-depth interviews using focus groups of healthcare professionals, who had at least 3 years of experience with children with FASDs. After purposeful recruitment, there were 26 healthcare professionals who participated in seven focus groups. **Results:** Several themes emerged from qualitative data analyses that revealed the importance of nutrition and presence of atypical eating behaviors related to co-occurring diagnoses with and without medications, hypo- or hypersensitivity to foods, selective eating, physical problems, food intolerances, sleep disturbances, late diagnosis, and nutritional deficiencies. The children's caregivers were also found to be under stress and in need of

nutrition education and improved feeding habits. **Conclusions and Implications:** The findings show that healthcare providers believe preschool-aged children with FASDs have varied complex manifestations of atypical eating behaviors that may increase the risk of malnutrition and require nutrition intervention for optimal childhood growth and development.

Introduction

Background information

Fetal alcohol spectrum disorders (FASDs) have been recognized in the Western Hemisphere as one of the foremost preventable causes of intellectual disability (Abel & Sokol, 1987; May et al., 2009; Smith, Jones, & Hanson, 1976). The Institute of Medicine defines FASD as a non-diagnostic term that represents collectively the adverse effects from prenatal alcohol exposure, including fetal alcohol syndrome (FAS) (Bertrand, Floyd, & Weber, 2005). Young children with FASDs are affected by an extensive range of permanent disabilities, depending on the quantity and timing of maternal alcohol consumption during the pregnancy. Recent research revealed that the U.S. prevalence of FASD is 2 to 5% in young school-aged children (May et al., 2014). The life-time cost, which includes healthcare services and productivity losses, of a child with FAS in the US has been estimated by the National Institute of Alcohol Abuse and Alcoholism to be \$2 million per person (Lupton, Burd, & Harwood, 2004).

Children with FASDs have chronic physical, behavioral, and developmental disabilities from prenatal alcohol exposure (Bertrand et al., 2005). Abnormalities that occur in children with FASDs, such as gastrointestinal dysfunction, facial structural anomalies, delayed development, poor motor control/skills, and co-occurring disorders (e.g. intellectual disability, autism (ASD), and attention deficit hyperactivity disorder) have been reported to adversely affect nutrition and eating (Itthagarun, Nair, Epstein, & King, 2007; Kalberg et al., 2006; Nanson & Hiscock, 1990; Uc et al., 1997; Wattendorf & Muenke, 2005). The Academy of Nutrition and Dietetics posits that children with developmental disabilities and special health care needs are at nutritional risk and require

intervention for malnutrition (American Dietetic, 2004). Although relationships between maternal-fetal nutrition and FASD have been under review, less is known about the nutrition and eating behavior in children with FASDs.

Anecdotal guides for caregivers and healthcare professionals list age-specific eating strategies as important in the nutrition care management of children with fetal alcohol spectrum disorders (Graefe, 1998; "Strategies for Children (3-12) with an Fetal Alcohol Spectrum Disorders," 2011; "Strategies for daily living," 2001-2004). Research by Werts et al. has described children with FASDs, aged 4 to 14 years, as selective eaters with satiety problems (Werts, Van Calcar, Wargowski, & Smith, 2014). It has also been noted by Fuglestad et al. that the diet in children with FASDs, aged 2 to 5 years, lacked crucial nutrients (e.g., omega-3 fatty acids, choline, and vitamins D, E, and K) necessary for neurological maturation (Fuglestad et al., 2013). There is evidence of nutrition and eating problems associated with FASD but characterization of atypical eating behavior in children with prenatal alcohol exposure is still in its early stages.

Since alcohol-related deficits apparent during childhood are manifested in a very broad spectrum and difficult to measure through traditional quantitative measures, qualitative methodology was used to explore the phenomenon of eating behavior in young children with FASDs. Specifically, the purpose of this qualitative research was to contribute to the fundamental knowledge of how eating behaviors are characterized in preschool-aged children with FASDs. The overriding research question guiding this study was: "How are eating behaviors manifested in children with fetal alcohol spectrum disorders?"

This exploration was accomplished through focus group interviews of healthcare professionals involved with FASD healthcare management and services (e.g., individual

therapy and family counseling). The use of focus groups has proven to be an effective qualitative methodology that allows for a disciplined inquiry about a desired topic. Focus groups have been successfully used in prior FASD research, such as in a study on FAS/FASD prevention in Russia by Balachova that sought to better understand the predispositions related to maternal alcohol consumption (Balachova, Bonner, Isurina, & Tsvetkova, 2007). In this study, healthcare professionals were chosen as the key participants in the focus groups because they would have contact with children experiencing higher degrees of FASD deficits and observe a variety of atypical eating behaviors. After investigating the healthcare professionals' views and experiences describing the atypical eating behavior, the findings will aid in the development of nutrition interventions to address the specific atypical eating behaviors in children with FASDs in an effort to limit or reduce the adverse effects of FASD on growth, and development in childhood.

Method

This qualitative study was embedded in the research design of the project, *Eating Behavior in Children with FASDs: A Mixed Methods Study*. In addition to the focus group interviews with healthcare professionals, the larger research project included an online survey for caregivers of children with FASDs. The results of the quantitative online survey are reported elsewhere. The principal investigator (PI) was used as the human instrument in this qualitative research by acting as moderator of the focus group and maintained a neutral position in the focus group interviews and the settings. For the purposes of the study, the healthcare professions included, but were not limited to, physicians, physician assistants, nurse practitioners, registered nurses, physical therapists,

occupational therapists, speech language pathologists, counselors, social workers, and registered dietitians. The two criteria for inclusion in the study were that the healthcare professional must be over the age of 18 years and have at least 3 or more years in experience with children with FASDs, aged 3 to 5 years. Monetary compensation was given to each professional for the time and effort involved when participating in the focus group. The study received approval from the Oklahoma State University Institutional Review Board.

Participants

There were 24 (92%) females and 2 males (8%) in the focus groups, who had an average of 15 years ($SD=8.5$) in practice and an average age of 45 years ($SD=10.9$). Of the 33 healthcare professionals who responded to the recruitment email, three (12%) were excluded due to having less than 3 years of experience. The remaining four (15%) were unable to participate due to variations in scheduling.

Recruitment

The healthcare professionals were recruited through purposeful criterion and snowball sampling from January to November 2014, at which time data saturation was reached. One means of recruitment was through electronic communications sent to healthcare professionals, who had attended continuing education programs offered through the Centers for Disease Control and Prevention regional fetal alcohol syndrome training centers, with prior permission obtained from the center's directors. Recruitment measures also entailed contacting online national and state FASD organizations and local Oklahoma healthcare professionals, who were employed at child study centers, adoption agencies, and state human service agencies. Once healthcare professionals qualified for

the study, each received an electronic communication regarding the scheduling of a focus group at a location and time most convenient for them.

Procedures

Qualitative inquiry in the focus groups addressed the underlying research question, “How are eating behaviors manifested in children with FASD?” A topic guide of questions for data collection was developed by the researchers and piloted through individual interviews with healthcare professionals at a child study center (Table 1). The guide format consisted of open and semi-ended questions to allow for expression of the healthcare professionals’ personal views and experiences. The primary questions included in the study are in Table 1. During the focus group interviews, when indicated, the moderator of the focus group asked follow-up questions for clarification or to encourage discussions.

Table 1. Topic guide of focus group questions for healthcare professionals regarding eating behavior in children with FASDs, aged 3 to 5 years

- If I visited your office/clinic, what would be a typical day in providing care to a child with FASD?
 - Would you please describe your most memorable experience in caring for a child with FASD?
 - When caring for children with FASD, what is your understanding of their nutritional status?
 - In relation to nutrition, how would you perceive that the disabilities associated with FASD-might or might not influence the children’s eating?
 - If children with FASD have eating problems, how do you think your profession
-

might or might not care for these problems?

- Overall, what are your views regarding the eating behavior of children with FASD?
-

To encourage participation of a wide variety of healthcare professionals, both online or onsite focus groups were conducted. The groups ranged from 2 to 7 participants per discussion and consisted of four online conferences through the video chat software, ooVoo LLC (New York, NY) and three at onsite locations (e.g., regional and state FASD conferences and worksite). Each participant in the focus groups received instructions regarding the ethical issues of their participation in the study, such as confidentiality, privacy, and the voluntary nature of the study. The focus group interview lasted approximately one hour with participants informed that the discussion was audio or video recorded with field notes taken by the focus group moderator.

Qualitative data analysis

The focus group interviews were maintained on audio and video recordings and transcribed verbatim by the PI to document and capture healthcare professionals' perceptive responses to the research question. Until transcription of the focus group interviews, audio tapes and flash drives were designated by an identification number without personal identifiers and placed securely in a locked file drawer in the Co-PI's office. After completion of the manuscript, they were erased. In each focus group transcript, the identification of speakers was by a number assigned according to their order of speaking and was without personal identifiers. The content of the focus group transcriptions was carefully read, compared, coded, and analyzed systematically several

times using thematic analysis techniques to identify emerging themes and constructs, regarding the eating behavior in children with FASD (Law et al, 2007). The frequency of answers to the questions in the topic guide was determined and summarized for all of the focus groups. From the data extraction, codes were determined to categorize and condense into prevalent themes by the PI and Co-PI.

Establishing trustworthiness, credibility, and transferability

Trustworthiness was attained through independent reviews of the findings by the PI and Co-PI to check for blind spots or selectivity in interpretation. To establish credibility, healthcare professionals in the focus groups were asked if one member would volunteer to review their group's respective transcript and identified themes for accuracy of the findings. Member checks were in agreement with the transcripts and themes from the qualitative analysis. For transferability, a thick description was provided regarding the views and perspectives of the healthcare professionals in the focus groups. The findings were also compared to previous published qualitative and quantitative research to identify similarities.

Results

Socio-demographic characteristics of the healthcare professionals

Socio-demographic characteristics of the healthcare professionals and the children with FASDs that had been under their care are in Tables 2 and 3. Based on the questionnaire responses, nutritional deficiencies and eating problems in preschool-aged children with FASDs were recognized by the majority of healthcare professionals (69%, n=18, 85%, n=22, respectively).

Table 2. Socio-demographic characteristics of healthcare professionals in the focus groups (n = 26)

| Variables | % (n) |
|--|-----------|
| Profession | |
| Physician, Physician Assistant, and Nurse Practitioner | 22.8 (6) |
| Psychologist | 11.5 (3) |
| Occupational Therapist | 7.7 (2) |
| Speech Language Pathologist | 7.7 (2) |
| Social Worker | 7.7 (2) |
| Licensed Professional Counselor | 15.2 (4) |
| FASD parent counselors | 7.7 (2) |
| Dietitian | 3.8 (1) |
| Other | 11.4 (3) |
| Researcher, International FASD organization Board Member, Project Coordinator for Parent Child Interaction Therapy | |
| Type of practice (select all that apply) | |
| Solo | 9.5 (2) |
| Group | 9.5 (2) |
| Community | 24.0 (5) |
| Faculty | 38.0 (8) |
| Other | 19.0 (4) |
| Practice (select all that apply) | |
| Rural | 19.2 (5) |
| Suburban | 38.5 (10) |
| Urban/Inner City | 42.3 (11) |
| Urban/Not Inner City | 34.6 (9) |
| Other | 7.7 (2) |
| Location of practice (select all that apply) | |
| United States | |
| Colorado | 3.8 (1) |
| Kansas | 15.4 (4) |
| Maine | 3.8 (1) |
| Maryland | 3.8 (1) |
| Minnesota | 15.4 (4) |
| Missouri | 7.7 (2) |
| Nebraska | 3.8 (1) |
| Oklahoma | 30.8 (9) |
| Oregon | 3.8 (1) |
| Wisconsin | 3.8 (1) |
| International location of practice | |
| Netherlands | 3.8 (1) |

Table 3. Socio-demographic characteristics of children with FASDs, aged 3 to 5 years, under the care of the healthcare professionals in the focus groups

| | % (n) |
|-----------------------|-----------|
| Ethnicity of children | |
| African American | 61.5 (16) |
| Asian | 30.8 (8) |
| Hispanic | 38.5 (10) |
| Native Hawaiian/Other | 26.9 (7) |

| | |
|--|-----------|
| Caucasian | 76.9 (20) |
| Native American/Alaskan | 7.7 (2) |
| Socio-economic level of children (select all that apply) | |
| Low | 61.5 (16) |
| Middle | 73.1 (19) |
| High | 46.2 (12) |
| Unknown | 15.4 (4) |
| Caregiver's relationship to children | |
| Biological | 42.3 (11) |
| Adoptive | 76.9 (20) |
| Foster | 61.5 (16) |
| Other (grandparents) | 3.8 (1) |
| Unknown | 3.8 (1) |

Key Themes of Qualitative Inquiry

The results show that children with FASDs had nutritional issues and atypical eating behaviors that, not only affected them, but also impacted their families. Several key themes and sub-themes emerged and were categorized as either originating with the child or the family. The key constructs expressed by the healthcare professionals were: (1) Proper nutrition and eating are important in children with FASDs, (2) Children with FASDs have atypical eating behavior related to behavioral and physical problems, (3) The families experience stress when feeding the children with FASDs. The themes identified the children's eating problems emanating from co-occurring diagnoses with and without medications, hypo- or hypersensitivity to foods, selective eating, physical abnormalities, food intolerances, sleep disturbances, late diagnosis of FASD, and nutritional deficiencies. The issues in the families occurred from stress and a need for additional nutrition education and improved feeding habits.

Construct 1: Proper nutrition and eating are important in children with FASDs.

Responses to question 3, "*When caring for children with FASD, what is your understanding of their nutritional status?*" revealed the theme, *the importance of*

nutrition (Table 4). Nutrition was viewed by the healthcare professionals to be an important consideration in the care of children with FASDs:

“Typically it (nutrition) has had an under-recognized role in the behaviors that we see in children with fetal alcohol..... And, to me, the discussion about nutrition is vital for the health of this ongoing consideration.” (HP2)

“As a speech pathologist, I find that it is very important to figure out nutritionally what they are eating and how they are reacting with it.” (HP5)

There was a concern that, if there was inadequate nutrition, the children’s problems would be affected even more.

“I think very many of them (children with FASDs) continue to develop more brain damage or developmental delay because they don’t get the nutrition they need to grow and develop.” (HP6)

Construct 2: Children with FASDs have atypical eating behavior related to many physical and behavioral problems.

The healthcare professionals provided insight into the challenges the children with FASDs had with eating, in regards to the questions, *“In relation to nutrition, how would you perceive that the disabilities associated with FASD might or might not influence the children’s eating?”*

Theme 1: Co-occurring diagnoses with and without medications

The healthcare professionals explained that there was a high correlation of attention deficit hyperactivity disorder, oppositional defiant disorder, and reactive attachment

disorder with FASD. The healthcare professionals felt the maladaptive behaviors associated with the co-occurring diagnoses affected the child's eating pattern, causing a poor oral intake.

“There are a lot of issues just sitting at the table. I think these kids have such behavior and attention difficulties that they won't sit for 15 to 20 minutes to have a meal. So, they run in and out.” (HP19)

The children were said to eat poorly when a change interrupted their daily routines, especially, if the event ended in a 'meltdown'.

“Research links stress with difficulties in self-regulation. So, if your child is having a rage at the table, he can completely lose touch with appetite cues.” (HP9)

There was also atypical eating behavior in the children with FASDs with hoarding of food, which was attributed to the children's hunger when coming off stimulant medications. If there were issues with the caregivers about the amount of food eaten by the children, the children hid the food to eat later.

“What happens very often is that... they are on the stimulant and come home from school and the stimulant has worn off. Now, they are ravenous like somebody coming off of speed. They are looking everywhere for food. It looks like hoarding. It looks like they are stealing food. They are hiding it. There is a lot of back and forth with the parents because the parents don't like them hiding the food. Then, that creates an additional level of eating issues because they have to hide it because their parents don't want them to eat.” (HP26)

The healthcare professionals also expressed that the medications to treat the maladaptive behavior in the children affected nutrition and eating.

“The standard practice out here anyway is that, if the child gets diagnosed with ADD, which 80% of children with fetal alcohol are being diagnosed with ADD, the first intervention is medicinal. A lot of time these medications are appetite suppressants.... The child may not appear to be hungry or eat a few bites. Are they on medications? What medications? How many medications? I have some kids that are on 7 to 9 medications and that is a problem in itself.” (HP2)

Theme 2: Hypo- or hypersensitive to foods

Children with FASDs, as indicated by the healthcare professionals, experienced a hypo- or hypersensitivity to the textures, smells, and tastes of food. The children’s eating patterns were dependent on the specific type of sensory issue.

“The sensory processing aspect of it, I think, can go both ways in terms of hypo- and hyper-responsive and even one child with FASD may have both to different stimuli.” (HP4)

With sensory dysfunction, the children had aversions to offending foods because of their particular food and texture preferences. Many of the children preferred soft or pureed, malleable foods that were not ‘crunchy’ or hard, especially avoiding foods with seeds (i.e., strawberries). While, on the other hand, some of the children rejected ‘mushy’ food. The healthcare professionals’ views were the children lacked a good nutritional base because of the aberrant sensory processing, which led to an inadequate variety of foods in the diet.

“We (occupational therapists) are thinking, if they are not eating, that it is a sensory issue, which often causes children to not eat a lot of food or to eat similar foods over and over again, resulting in the children having strong food preferences... The eating patterns are based on their sensory issue. I see children that have preferences where they prefer to drink from a straw or have a temperature or smell preference. Some kids don’t like juice because it has such a strong odor to it.” (HP3)

Theme 3: Selective eating

The children with FASDs were described by healthcare professionals as being selective eaters and rigid in what they ate. The children refused to eat unfamiliar foods because they adamantly ‘stuck’ to the preferred food.

“Once they get something they like, these kids with FASD, they stick with it. So they don’t want to change to another food or another color of a food. They like their mashed potatoes and their white bread so their ability to do other things is less.”

(HP22)

“We get some very picky eaters (children with FASDs) that will only eat chicken nuggets, French fries, and pizza. You know there are nutritional issues when they only eat things that are white.” (HP23)

It was believed that the selective eating was similar to other children that have neurobehavioral disorders.

“The problems are multi-faceted and, specifically within the area of nutrition, we have started to see both clinically and in our research that these kids (children with

FASDs) have, like other kids that have neurodevelopmental disorders, some abnormalities in the eating patterns, their eating preferences, and their control issues around food.” (HP24)

Theme 4: Physical abnormalities and somatic symptoms

Subtheme 1: Growth issues

Many of the children with FASDs were described by healthcare professionals as small in stature and underweight but, when approaching adolescence, some of the children developed overweight or obesity. It was stated that the males tended to remain small, while the girls developed an extra layer of adipose tissue during adolescence.

“When they reached the adolescent years, they seemed to have higher rates of obesity.” (HP24)

“Collectively, the children that have been exposed to alcohol prenatally have been small and underweight. Some have been identified with failure to thrive.” (HP4)

Subtheme 2: Gastrointestinal Dysfunction

It was noted by the healthcare professionals that the children with FASDs had poor gastrointestinal (GI) function, which could lead to constipation, nausea, vomiting, and/or acid reflux, thereby, discouraging or reducing food intake.

“One other thing that I might add is the underlying issues, such as the gut. It is the medical side of it. If there is a problem with digestion that leads to bloating or to some sensation that they feel during a meal, a 3 to 5 year old is not going to be able to tell you

that “Oh, that makes my tummy hurt” or “I don’t feel good after eating something.”
(HP26)

The healthcare professionals felt some of the somatic GI symptoms, such as constipation and the increased satiety, resulted from the adverse side effects of the children’s medications.

“Let alone their ability (in reference to the children taking medicines) to have bowel or bladder function. And not be constipated.” (HP4)

“In many kids, it is part of their biological make-up, problems with digestion, problems with elimination.....” (HP13)

Subtheme 3: Poor motor tone and skills

As accounted by the healthcare professionals, the children with FASDs had overall lower muscle tone, muscle strength, and endurance, which influenced both gross and fine motor skills. Some children were unable to maintain posture and control their body while eating.

“Yes, difficulty in picking up food and using utensils is an issue for sure, more so, in just a child holding their posture to eat.” (HP 4)

“Depending on how much alcohol exposure there was in utero, how much oral motor issues they are having.... Then, they are going to have different nutrient deficiencies than another child.” (HP11)

Subtheme 4: Central nervous system dysregulation

FASD was defined by healthcare professionals as a ‘brain-based’ physical disability that affected the children’s basic needs, such as eating behavior. Eating behavior was described, by one healthcare professional, as a basic core function under the influence of the hypothalamus and higher executive functions.

“Eating behavior is a very basic core function, a hypothalamic function, but the behaviors around eating, like being able to sit and have a social interaction while eating with your family, being flexible when you try things, understanding that you have to try things more than once before you grow to like, those require higher levels of cognitive functions.” (HP24)

It was understood by healthcare professionals that children with FASDs required more nutrition to support brain development and function.

There is current research going on that is showing that, when brains are disorganized (from FASD), the brains have to work much harder to accomplish its tasks. Of course, the brain uses more nutrition than any other part of the body as I understand it.” (HP2)

Because of neurological deficits, the children with FASDs were said to be at higher risk for seizures and lacked sensation to pain.

“....the kid (child with FASD) doesn’t feel pain or is cutting themselves with knives... trying to feel something.” (HP6)

Along with the dulled senses, their appetite was also affected.

“It is literally that his body (boy with FASD) doesn’t sense hunger.” (HP8)

Theme 5: Food intolerances

The healthcare professionals observed food intolerances to wheat and dairy products in the children with FASDs. Due to the food intolerances and allergies, the children received special diets and vitamin supplementation.

“...the gluten free milk free (diet), I think it kind of lifted the fog from their development problems and I think the B vitamins were very important here.” (HP6)

“....some the kids are lactose intolerant. I also think there is an adult selection of what the children should or shouldn't eat based on the child's behavior and the general public ideas that go around about what kind of foods cause what kind of behaviors.” (HP25)

There were also additives and dyes in foods (i.e., red dyes), which caused food allergies and cravings in the children with FASDs.

“In addition to what are we feeding the kids, is it GMOs...are there additives...what about dyes? Yes, because a lot of the complaints that I have heard from parents and comments that I have heard professionals are around the additives in the foods, not just the nutritive value of the food.” (HP2)

“I see a lot of food allergies. Kids that just crave that white food or ears turn red after they have a little bit of Red 40.” (HP23)

Theme 6: Sleep disturbances

A relationship with sensory problems and inadequate sleep was discussed by the healthcare professionals in that the feeling of wearing pajamas or particular colors of the

bedding caused too stimulating of an environment to allow the child to fall asleep. Healthcare professionals felt that, when the children were getting enough sleep and nutrition, life was better for the entire family.

“When I talk with post-adoption specialists and do workshops in foster care and adoption, I hear that sleep is the number one issue for parents post-placement, and feeding problems are number 2.” (HP9)

“And, how something so simple, as where someone is sleeping or what they are wearing to bed, can have such a profound impact on the child’s homeostasis. I think that is something powerful and relates to the brain damage, lack of proper inhibition, and the neurobiological effects...When people are getting sleep and probably the same thing with nutrition, life is just better when everyone is sleeping. So, everyone is going to be happier and healthier.” (HP3)

Theme 7: Late diagnosis of FASD

Healthcare professionals emphasized that the children were not receiving an early diagnosis of FASD because other behavioral problems, such as pervasive developmental disorders or ASD, were instead being diagnosed in the children.

“In all honesty, they are not getting diagnosed with that anymore (FASD) but with other comorbidities that go along with it. You are going to get the IUGR, the developmental delay, the PDD, ADD, and get all of the symptoms associated with it rather than the diagnosis.” (HP11)

“A lot of these kids are misdiagnosed with autism or vice versa.” (HP26)

This was especially apparent in the children with FASDs, who were adopted.

“...so, therefore, per the diagnostic clinic, the clinicians are unable to give a positive diagnosis (because with adoption there may not be a medical history of maternal alcohol consumption) but the psychiatrist, the other emotional delays, and the growth delays are all leading to that indication (a diagnosis of FASD). (HP8)

Theme 8: Nutritional Deficiencies

Another concern voiced by the healthcare professionals was about nutrient deficiencies in vitamin D and iron in the children with FASDs.

“I think a lot of kids are vitamin D deficient in general. I would suspect that in this group there are probably even more, especially if they are picky eaters they are not getting vitamin D... Another thing is that a lot of kids have a lot of non-anemic iron deficiency.” (HP25)

Construct 3: The families experience stress when feeding the children with FASDs.

Theme 1: Families of children with FASDs need improved feeding habits

The feeding of the children with FASDs, as noted by the healthcare professionals, revolved around the feeding habits of the family. Some feeding habits developed by the families, such as not having regularly-scheduled family mealtimes, led to a diet with reduced nutritional value in the children.

“A bag of chips and a can of soda and that is what they are eating (the children).” (HP15)

“I think sometimes it is a family issue because they don’t sit at a table or they don’t have cooked meals.” (HP18)

Theme 2: Stress in families

The families have told the healthcare professionals that they are under a lot of stress when raising their children with FASDs.

“It is so important we acknowledge how these parents are drained and tired themselves and we often don’t ... We, as clinicians, see them (the children with FASDs) for an hour a week or a couple hours a week. I don’t deal with the being tired these parents are so stressed.” (HP3)

“The parents were so stressed. They come in crying every time they begin to talk.” (HP17)

The families felt that they were ‘failures’ because they couldn’t get the child to gain weight, behave, or eat a variety of foods. Healthcare professionals heard from caregivers:

“My kid is a ‘failure to thrive’ and I (family member) feel like a failure.” (HP9)

Also, healthcare professionals rated difficulties with the atypical eating behaviors high in children with FASDs living in the adoptive or foster parent’s home.

“Within the foster/adoption community, I see higher rates of feeding problems than in the general population I work with, from food hoarding and preoccupation to sensory and oral motor problems and picky and selective eating.” (HP9)

“And, when they (the children) are new in the home, they (the foster parents) don’t know how to get this child, number one to behave and put their shoes on, much less eat something unfamiliar or doesn’t look like something my last mommy made.” (HP22)

The families were also relieved when they learned that the problems were from FASD and not because of their parenting.

“..part of the experience of working with these families is the relief when they learn..... that their children are not psychopaths and that the child has a sensory issue or that it is a brain-based deficit that the child is experiencing.” (HP3)

Theme 3: Caregiver’s need for additional nutrition education

The healthcare professionals had learned not to take it for granted that all of the caregivers had knowledge of what constitutes a healthy food.

“I often saw where parents gave children Fanta in a bottle and, when I started to ask, they thought it was the same as juice.” (HP3)

They realized that the families were stressed and had a need for additional nutrition education in an effort to improve the quality of the diet.

“So, the likelihood of them (caregivers) being able to have the luxury or maybe even the ability, but it is going to be both, of course, to think about what the nutritional content and setting of these children I think is very low.” (HP1)

“...if a person doesn’t know the difference between Fanta and a good juice, if that is not an oxymoron, then it might be useful to consider that there might be a different explanation. We need to be aware of the parent’s ability to have discourse or a

discussion to be able to understand. Because what their norm is maybe how they were raised....” (HP2)

Referral to specialized healthcare professionals

If the global or eating problems extended beyond their particular expertise, healthcare professionals advised the caregivers of children with FASDs to seek additional services from other healthcare disciplines, such as from child study centers for a diagnosis, occupational therapists for sensory issues, and Registered Dietitians for nutritional assessment.

“We, as PT (physical therapists), will screen for and know to refer back to our OT (occupational therapists) colleagues to work on specifically for the feeding specific sensory issues, textures, smell, touch...” (HP4)

“It is our standard policy to make referrals to the child study center if we know that the birth mother utilized alcohol during the pregnancy.” (HP11)

“I really feel strongly about the nutritional consultation. We don’t often think about a nutritional consultation with these kids but, when we think about giving medication that is going to increase their body weight or creating metabolic problems, we make sure that parents aren’t adding insult to injury by feeding them unhealthy foods at the same time. The parents need to be on board by feeding them balanced meals and minimizing the sugary snacks and things like that so they are getting good nutrition.” (HP26)

Closure of focus group

The focus group interviews were completed after asking, “Overall, what are your views regarding the eating behavior of children with FASD?” The healthcare professionals summarized their views on the atypical eating behavior in children with FASDs as:

“The interaction is a big one... between the child, where they came from before the age of 3 to 5, and what patterns were already put in place; and, then, also the attachments issues with the parents.... Sometimes parents use force or coercion or bribing and use all kinds of things that are maladaptive. Then, that causes the child’s eating behaviors to be maladaptive.” (HP26)

Discussion

To the researchers’ knowledge, this is the first qualitative study, using focus groups of healthcare professionals, to explore the atypical eating behavior of preschool-aged children with FASDs. The study identified the manifestations of atypical eating behavior in children with FASDs from the views of the healthcare professionals. Qualitative data analyses revealed themes related to the constructs of: (1) Proper nutrition and eating are important in children with FASDs, (2) Children with FASDs have atypical eating behavior related to behavioral and physical problems, and (3) The families experience stress when feeding the children with FASDs.

Proper nutrition and eating were viewed by the healthcare professionals as important in the care of children with FASDs, aged 3 to 5 years, especially, since adequate nutrition is necessary for optimal brain development (Rosales, Reznick, & Zeisel, 2009). Rosales, Resnick, and Zeisel discerned that, in the preschool-aged children with typical development, the lack of nutrition would adversely impact postnatal brain development and may lead to poor behavioral outcomes. However, the theme of a late diagnosis of

FASD suggests that ensuring proper nutrition may be hindered in preschool-aged children since the average age for evaluation of an FASD diagnosis is 9.9 years (Astley, 2010). In an effort to prevent further impairment in brain development and function, early identification of FASD, nutritional issues, and atypical eating behaviors is indicated in order to promote adequate nutrition in children during the preschool years (Rosales et al., 2009).

From the perspectives of the healthcare professionals, children with FASDs were found to have atypical eating behavior in association with behavioral and physical problems. A major theme emerged from this construct regarding how co-occurring diagnoses with and without medication treatment coexist in the children with FASDs and result in poor dietary intake. Previous research has shown that children with FASDs and/or ADHD, exhibit eating problems and appetite suppression, especially when treated with a stimulant medication (Doig, McLennan, & Ben Gibbard, 2008). A guide on FASD medications by Ozsafarti and Koren also documented that anorexia may be a side effect of stimulant medications (Ozsfarti & Koren, 2015).

Another major theme from the focus groups was that, secondary to the effects of prenatal alcohol exposure on sensory processing, children with FASDs, who were poor eaters, most likely were also experiencing either a hypo- or hypersensitivity to the tastes, smells, and textures of different foods. Sensory processing disorders are not uncommon in children with FASDs nor in the co-occurring FASD diagnoses of ASD (Carr, Agnihotri, & Keightley, 2010; Franklin, Deitz, Jirikowic, & Astley, 2008; G. Nadon, D.E. Feldman, W. Dunn, & E. Gisel, 2011). Research by Nadon, Feldman, Dunn, and Gisel substantiated that, in children with ASD, eating problems with oral sensitivities

were associated with sensory processing disorders (G. Nadon, D. E. Feldman, W. Dunn, & E. Gisel, 2011). However, oral sensitivities in preschool-aged children with FASDs that are related to the tastes, textures, and smells of food have not received much attention.

Selective eating was a theme of atypical eating behavior in the children with FASDs, which is also referred to as ‘picky eating’. Zucker et al. discovered in children with selective eating that often there are co-existing diagnoses of psychiatric (i.e., ADHD), sensory (i.e., hypersensitivity to smell and oral textures), and physical problems (i.e., growth deficiency), such as seen with FASD (Zucker et al., 2015). A relationship between selective eating and FASD has also been corroborated in the research of Werts et al., in which children with FASDs, aged 3 to 5 years, exhibited eating behaviors of food fussiness or picky eating (Werts et al., 2014). There is a concern that selective eating would limit the variety of foods in the diets of children with FASDs and lead to nutritional insufficiencies further impacting brain development (Fuglestad et al., 2013).

The theme of physical abnormalities and somatic symptoms is supported by a large number of prior research projects documenting somatic abnormalities in FASD (Bertrand et al., 2005; Church, Eldis, Blakley, & Bawle, 1997; Hofer & Burd, 2009; Itthagarun et al., 2007; Wattendorf & Muenke, 2005). In the focus groups, somatic problems of growth issues, GI dysfunction, poor motor development, and central nervous system dysregulation, were associated with the children’s eating problems. Further evidence exists in research by Werts et al. that reported eating difficulties, somatic symptoms, problems with chewing, and growth issues (i.e., underweight and obesity), in children with FASDs, aged 3 to 5 years (Werts et al., 2014). Research by Feinberg et al. also

explained that malnutrition should be under consideration in children with disabilities and GI problems; hence, somatic problems could adversely affect the nutritional status of children with FASDs (Feinberg, Feinberg, & Atay, 2008).

Another emergent theme from the healthcare professionals' discussions was sleep disturbance in children with FASDs from visual and/or tactile sensory problems. Prior studies on insomnia and sleep apnea in FASD show that sleep disturbances have been associated with sensory and neurological deficits (Chen, Olson, Picciano, Starr, & Owens, 2012; Jan et al., 2010; Wengel, Hanlon-Dearman, & Fjeldsted, 2011). The ramifications are that, if sleep problems persist in the preschool-aged children with FASDs, overweight or obesity may occur later in adolescence or adulthood, such, as described by El-Sheikh et al., in older children (i.e., 9 to 11 years) with typical development, who had increased BMIs with a lower quality of sleep (El-Sheikh, Bagley, Keiley, & Erath, 2014).

Lastly, inadequate dietary intake in children with FASDs was apparent in the themes of food intolerances and vitamin deficiencies. Food intolerance to wheat and milk were noted in the children with FASDs by the healthcare professionals and treated by placing the children on special diets restricting intake of gluten and lactose. Healthcare professionals also noted deficiencies in vitamin D and iron in the children that reflected insufficiencies in the diet, which would require nutritional supplements. Dietary deficiencies of choline, calcium, vitamin E, vitamin K, vitamin D, fiber, and essential fatty acids due to poor food intake in preschool-aged children with FASDs, have been reported by Fuglestad et al. (Fuglestad et al., 2013). However, food intolerances, special diets, and nutritional supplements have not been fully addressed in children with FASDs.

The construct that families experienced stress when feeding the children with FASDs was recurrent in the focus groups. One associated theme was stress in the families, particularly during mealtimes. The themes of caregiver's need for additional nutrition education and improvement of feeding habits were felt by healthcare professionals as contributing factors to the caregiver's stress and eating problems in the children. These findings were also noted by Werts et al. in families of children with FASDs that habitually snacked sugary foods and had difficulties in meal preparation (Werts et al., 2014). Based on the healthcare professionals' views, it is not an easy task to feed children with FASDs, which suggests nutritional education and counseling would be of assistance to caregivers.

Limitations

One major limitation of the study was access to qualifying healthcare professionals; however, to solve this problem, a wide range of notices were sent to healthcare professionals that had received continuing education at different FASD regional training centers and to online national and international FASD organizations. Of the professions represented, there were few nutritionists but this may be an indication that their job responsibilities did not include services to children with FASDs. Another limitation was the difference in healthcare disciplines within each focus group but this was also a strength since, as the different types of healthcare professionals interacted with each other, they were building upon each other's expressions and experiences. In a similar manner, professionals who commonly work with pediatric feeding issues are predominately female; however, male healthcare professionals also participated in the study.

Conclusion

The results of this qualitative research strongly indicate that there are atypical eating behaviors in children with FASDs that are complex and related to the behavioral, physical, and mental disabilities. Healthcare professionals recommend the provision of dietary advice and nutrition intervention to families who have children with FASDs. Findings from this research support the need for further investigation into the atypical eating behavior of children with FASDs, especially in regards to sensory sensitivities, food intolerances, nutritional supplementation, special diets, medications, and the need for more access to nutrition services.

Implications

Future research is indicated to investigate the eating behavior of children with FASDs to determine the impact of the behaviors on nutritional status and family function. Investigations may test for associations between atypical eating behaviors and sensory processing, cognitive function, and family quality of life. Nutrition education and intervention for families of children with FASDs could include Ellyn Satter's philosophy on the *Division of Responsibility* between the caregiver and child in the feeding process (Satter, 2007). From nutrition screening and further studies, nutrition strategies could be designed to individualize nutrition intervention for children in an effort to mitigate the adverse effects of FASD to improve the nutritional status, health, and functioning of children with FASDs.

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CHAPTER VI

Summary

Children with FASDs have growth issues, physical abnormalities, and maladaptive behaviors, which could affect nutrition and eating (U.S. Department of Health and Human Services, 2009). However, there is a little evidence-based literature specifically addressing the eating behavior in children with FASDs. This doctoral dissertation research used a mixed methods approach to investigate the eating behavior in children with FASDs, aged 3 to 5 years, through the perspectives of caregivers and healthcare providers. In nutrition research, the preschool age is an important developmental period with a major transition to independent eating (Samour & Helm, 2005). The rationale for this research was that, upon identification and characterization of atypical eating behavior, appropriate feeding strategies can be identified and tested for specific nutrition intervention and education to limit or reduce the adverse effects of FASD on nutrition, growth, and development in childhood.

The central hypothesis of this dissertation was that preschool-aged children with FASDs exhibit atypical eating behavior, which can be defined by their caregivers and healthcare professionals. The hypotheses addressed were:

Hypothesis 1. The *hypothesis* was that caregivers would report atypical eating behavior in children with FASDs, aged 3 to 5 years, as assessed online by socio-demographic characteristics, children's anthropometric measurements, and the CEBQ (Wardle, Guthrie, Sanderson, & Rapoport, 2001).

Hypothesis 2. The *hypothesis* was that caregivers would report atypical eating behavior in children with FASDs as assessed online by the CEBQ (Wardle et al., 2001), which will be positively associated with increased behavioral problems as reported online by the CBCL/1.5 – 5 (Achenbach & Rescorla, 2000).

Hypothesis 3. The *hypothesis* was that healthcare providers in focus group discussions would report encountering children with FASDs who have atypical eating behaviors that affect their health or development.

The research hypotheses were tested and below are discussions of the findings in this dissertation research.

The findings supported the first hypothesis that caregivers would report atypical eating behaviors in preschool-aged children with FASDs. Seventy-four caregivers reported in the CEBQ observations of their children's eating and defined the children's eating behaviors as atypical, which was evident in the high levels of excessive need for drinks, slower eating, and selective eating. The study also found that the children with FASDs were significantly different in Desire to Drink, Food Responsiveness, Emotional Overeating, Food Fussiness, and Enjoyment of Food when compared to the normative sample scores of the CEBQ (Wardle et al., 2001). In addition, there were differences in weight status. When compared to U.S. estimates, the caregiver-reported anthropometric

measurements of the children with FASDs were statistically different in the abnormal (or not normal) weight and low birth weight categories (Ogden et al., 2014; U.S. Department of Health and Human Services Maternal Child Health, 2014). The study findings are reinforced by the research of Werts et al., which recounted that children with FASDs had nutrition and eating problems of a poor appetite, selective eating, diets high in sugar, frequent snacking, and weight issues of underweight and obesity (Werts, Van Calcar, Wargowski, & Smith, 2014). A high sugar diet may be related to an excessive need for sugar-sweetened drinks. In a cross-sectional study by Nickelson et al., it was noted that excessive drinking of sugar-sweetened beverages (i.e., increased desire to drink) should, in fact, be addressed before the preschool years in view of the long-term increased risk of overweight and obesity (Nickelson, Lawrence, Parton, Knowlden, & McDermott, 2014). It appears that children with FASDs may be at increased risk of eating problems and weight issues, which, if persistent, could lead to an increase or decrease in appetite and, either, underweight or obesity tendencies.

The findings supported the second hypothesis that atypical eating behavior was associated with higher levels of global behavioral problems in children with FASDs, aged 3 to 5 years, and an indication that the condition severity of FASD may underlie the atypical eating behavior. Fifty-four caregivers completed both the Children's Eating Behavior Questionnaire (CEBQ) and Child Behavior Checklist 1.5-5 (CBCL/1.5-5) in the online survey and characterized the eating behavior of 59 children with FASDs. As reported by the caregivers, children with FASDs commonly displayed a slower eating rate or lack of interest in eating, which was related differently to somatic symptoms and medications. It was found to be slower in the children with somatic complaints but faster

if the children taking a greater number of medications. The second highest reported CEBQ subscale, selective eating, was associated in children with FASDs, who had more problems with internalizing behaviors and sleep disturbances. Along the same lines, there was more emotional undereating in children with FASDs, who had higher levels of internalizing behaviors; whereas, more aggressive behavior in the children was related to greater emotional overeating. In support of the findings in this study, research by Lewinsohn et al. reported that selective eating in 3-year-old children from a community-based sample was correlated with mothers who were chronic alcoholics (Lewinsohn et al., 2005). Research has also established the prevalence of sleep difficulties in children with FASDs but have not fully identified the effects of poor sleep on the children's health, nutrition, and eating (Chen, Olson, Picciano, Starr, & Owens, 2012; Ipsiroglu, McKellin, Carey, & Looock, 2013; Jan et al., 2010). Similarly, in a population-based sample, Mackenbach et al. observed that preschool children with emotional and behavioral problems had more inhibited eating behaviors in relation to a reduced BMI, while also demonstrating correlations between internalizing behaviors and emotional undereating in the same group of children (Mackenbach et al., 2012). Equally important, when treating the maladaptive FASD-related behaviors, it has been documented that the medications used can affect appetite and that behavioral problems often co-occur with poor adaptive function, sensory processing disorders, and adverse life outcomes in children with FASDs (Carr, Agnihotri, & Keightley, 2010; Doig, McLennan, & Ben Gibbard, 2008; Franklin, Deitz, Jirikowic, & Astley, 2008; Ozsarfaty & Koren, 2015; Streissguth et al., 2004). The relationship between atypical eating behaviors and global behavioral problems was discovered to be complex and appears to be dependent on the

specific eating problem, the type of global maladaptive behavior, and the number of medications. The results of this study imply that preschool-aged children with FASDs, who have a higher level of behavioral problems and medications, may exhibit atypical eating behaviors. The concern is that, if eating problems are present during the preschool years and not addressed, there is an increased risk of developing an eating disorder during the individual's lifespan (Kotler, Cohen, Davies, Pine, & Walsh, 2001). Yet, little attention has been directed towards relationships between disordered eating and FASD maladaptive behaviors.

The findings of the qualitative research supported the third hypothesis that healthcare professionals would report atypical eating behavior in children with FASDs, aged 3 to 5 years. The study explored, through focus groups of healthcare professionals, the eating behavior of preschool-aged children with FASDs. After purposeful recruitment, there were 26 healthcare professionals who participated in seven focus groups. Many of the healthcare professionals viewed nutrition as important in the care of children with FASDs. During the focus groups, healthcare professionals expressed that children with FASDs, who had more maladaptive behaviors and inattentiveness, ate less and were unable to sit during the entirety of a meal. In the treatment of the disruptive behaviors, healthcare professionals commented that stimulant medications given to the children may cause somatic symptoms affecting nutrition and eating, such as an increased or decrease appetite and constipation. In addition, the focus group interviews described how food intake and dietary quality in the children with FASDs was affected by a hypo- or hypersensitivity to the tastes, smells, and textures of different foods, selective eating, and the somatic problems of growth issues, GI dysfunction, poor motor development, and

central nervous system dysregulation. Other eating problems that were reported by the healthcare professionals included sleep disturbances, food intolerances/allergies to wheat and milk, and nutrient deficiencies in vitamin D and iron. Based on the healthcare professionals' views, the caregivers also contributed to the children's eating problems because, often, the family members were under considerable stress, had limited nutrition knowledge, and needed improvement of feeding habits. In support of the study findings, prior qualitative research has successfully explored the phenomenon of nutrition, eating behavior, and caregiver stress. Franssen et al. conducted semi-structured interviews of healthcare professionals evaluating malnutrition in individuals with intellectual disabilities, while research by Mita et al. examined the views of teachers on mealtime behavior in preschool children (Franssen et al., 2011; Mita, Gray, & Goodell, 2015). Caley et al. qualitatively explained, through an analysis of public transcripts, the effectiveness of a classification tool to assess the difficulties experienced by caregivers of children with FASDs (Caley, Winkelman, & Mariano, 2009). However, nutrition and eating behaviors in children with FASDs have not fully been explored as to specific associations with FASD impairments and medications. From the healthcare professionals' perspectives, atypical eating behavior in preschool-aged children with FASDs was manifested in complex and interconnected relationships between neurobehavioral disabilities, physical impairments, and stressed family dynamics. Nutrition referrals to dietitians and strategies, such as nutrition supplements and special diets, were implemented by the healthcare professionals to address atypical eating behaviors but evidence-based research is indicated in order to determine optimal nutrition strategies to improve the children's atypical eating behaviors.

The central hypothesis of this dissertation research was supported through the identification and characterization of atypical eating behavior in children with FASDS, as defined by the caregiver responses to the online survey and the focus groups of healthcare professionals involved in FASD pediatric care management. Although evaluated separately, caregivers and healthcare professionals expressed the presence of similar atypical eating behaviors in the children, which were attributed to the wide spectrum of disabilities and impairments associated with FASD. Behaviors that can either stimulate or inhibit eating were distinguished by the caregivers and healthcare professionals in relation to a complexity of issues involving higher levels of global behaviors problems, physical or somatic complaints, sensory dysfunction, sleep problems, co-occurring diagnoses, and medications.

Slower eating or disinterested eating is an inhibitor of food intake that was a commonly reported atypical eating behavior by both the caregivers and healthcare professionals (Wardle et al., 2001). From the caregiver responses, slower eating was demonstrated to have inverse associations with somatic symptoms and medications. As explained by healthcare professionals, this was related to the lack of interest in eating from underlying gastrointestinal issues, somatic symptoms of constipation, and the nutritional side effects of the children's medications that may affect appetite. Studies have documented that children with FASDs have somatic and functional defects of the gastrointestinal tract (GI) and may receive one or more medications, particularly in treatment of maladaptive behaviors (Doig et al., 2008; Hofer & Burd, 2009; Jones et al., 2010; Ozsarfati & Koren, 2015; Werts et al., 2014). Yet, there are limited studies that

have specifically shown the impact of somatic symptoms and medications on eating in children with FASDs.

Another food avoidance behavior in the children with FASDs commonly described by the caregivers and healthcare professionals was the atypical behavior of selective eating (Wardle et al., 2001). Caregivers reported selective eating in the children with FASDs that was correlated with higher levels of internalizing behaviors and sleep disruption. This was supported by the healthcare professionals, who had encountered children with FASDs exhibiting picky eating and sleep difficulties, which were thought to be associated with neurobehavioral problems and sensory dysfunction. Prior research has shown that children with FASDs have neurobehavioral problems, sensory processing disorders, and sleep difficulties; however, the relationship between these problems and eating behavior have yet to be fully investigated (Carr et al., 2010; Chen et al., 2012; Nanson & Hiscock, 1990).

Undereating during emotional stress was determined to occur in children with FASDs by the caregivers and healthcare professionals. From the caregiver responses, this undereating was found to have an association with higher levels of internalizing behaviors in children with FASDs. Healthcare professionals reinforced the occurrence of undereating, when emotionally stressed, in the children with FASDs, especially, when the children encountered changes in their environment that led to a loss of appetite during a ‘meltdown.’ A study by Mackenbach supports the association between emotional stress and atypical eating behaviors that inhibit food intake, which, consequently, may lead to underweight tendencies in children (Mackenbach et al., 2012).

At the opposite end of appetite regulation, overeating during emotional stress was noted in children with FASDs from the responses of the caregivers and healthcare professionals (Wardle et al., 2001). As reported by the caregivers, there were correlations between stress overeating and children with FASDs who had higher levels of externalizing behaviors. The views of the healthcare professionals reaffirmed the presence of overeating when stressed in some children with FASDs, particularly, when the effect of a stimulant psychiatric medication was declining and resulted in an increased appetite and hoarding of food. Prior studies have indicated that increased weight and overeating in children with typical development were associated with externalizing behaviors, such as hyperactivity, inattentiveness, and aggressive behaviors (Anderson, He, Schoppe-Sullivan, & Must, 2010; Khalife et al., 2014). A concern is that, if overeating during stress persists, children with FASDs would have an increased risk of overweight and obesity during their life span.

Additional atypical eating behaviors were delineated by either the caregivers or the healthcare professionals, which may adversely affect nutrition in the children with FASDs. The caregivers reported that that children with FASDs were high in excessive drinking, which research suggests is a behavior that may increase the risk of overweight and obesity if the excessive drinks consumed are mostly sugar-sweetened beverages (Nickelson et al., 2014; Wardle et al., 2001). The healthcare professionals included nutritional deficiencies and difficulties in the family as part of the eating problems and instituted strategies to improve the nutrition and feeding in children with FASDs. Stress during mealtime preparation and poor feeding habits have previously been identified in

the caregivers of children with FASDs; thereby supporting the need for specific nutrition education programs targeting caregivers of children with FASDs (Werts et al., 2014).

Due to the atypical eating behaviors identified and characterized by the caregivers and healthcare professionals, there are implications that children with FASDs may experience poor dietary intake, nutritional insufficiencies, and weight issues in association with global maladaptive behaviors, somatic complaints, co-occurring diagnoses, and medication. Early nutrition assessment and intervention are indicated to address the complex eating behaviors in children with FASDs in an effort to improve growth and development in children with FASDs.

Strengths and Limitations

A major strength of the study was that the caregivers and healthcare professionals of preschool-aged children with FASDs represented a broad area across the U.S. and some internationally. In the study, caregivers and healthcare professionals were primarily females but males were also included. Even though the age range of the children was narrow and may limit generalization, the study addressed an important stage in child development when adequate nutrition is particularly important for the developing brain. The study's online cross-sectional survey may not permit causal identification but does give evidence of associations. Although the data from the survey were self-reported and may reflect the need for social desirability, participants were instructed their anonymity would be maintained without personal identifiers. Participation of caregivers may have also been limited due to the survey being online but the snowballing approach was used for a wider outreach in recruitment. The questionnaires used in the study may not have fully described eating and global behavioral problems in the children but they have been

successfully used together in prior research projects. In addition, the co-occurring diagnoses and medications noted in the children, as reported by the caregivers, were not professionally confirmed or verified but, since listed specifically by the caregivers, were considered meaningful and included in this study. Another limitation was gaining access to healthcare professionals whose responsibilities included preschool-aged children with FASDs. To broaden recruitment, mailing lists were used from healthcare professionals, who had participated in continuing education at FASD regional training centers, along with emails sent to both online national and international FASD organizations, such as National Organization for FAS and the European FASD Alliance. Even though recruitment was from purposive sampling, data saturation was attained in this study.

Applications and implications for further research

The study findings indicate that early nutritional assessment and intervention by registered dietitian nutritionists is important in the care management of preschool-aged children with FASDs. Ideally, nutrition assessment would occur during infancy to troubleshoot for developing problems related to nutrition and feeding. Since there have been reports of poor suck and failure to thrive in infants with FASDs, the caregiver could receive counseling on the identification of effective nipples and formulas to institute a successful feeding (Kvigne, Leonardson, Borzelleca, Neff-Smith, & Welty, 2009; Services, Prevention, Disabilities, Centers, & Syndrome, 2009). In an effort to address the eating problems in preschool-aged children, strategies to improve eating could include nutrition education for their caregivers based on Ellyn Satter's *Division of Responsibility* (Satter, 2007). For example, caregivers would receive advice on the provision of regularly scheduled snacks and family mealtimes, so the child would learn

how to competently eat and manage hunger or satiety. If there are issues with selective eating in the child with FASD, the caregiver would be encouraged to continue offering non-preferred foods on several different occasions, while, at the same time, providing a food that is familiar. As an approach to reduce excessive drinking, suggestions to the caregiver may include substituting healthy options, such as water or low-fat milk, in place of sugar-sweetened beverages and limiting fruit juice to six ounces per day.

With the identification of atypical eating behaviors in children with FASDs, tailored nutrition intervention for the children and nutrition education for their caregivers can be developed to ensure childhood dietary requirements, while supporting the family dynamics. Further investigations may focus on a more complete nutrition assessment to identify relationships between specific issues, such as with medications, sensory disorders, and co-occurring diagnoses, in an effort to improve the development and quality of family life in children with FASDs.

Conclusion

Eating behavior in children with FASDs, aged 3 to 5 years, was determined to have the same complex, interconnected, and varied path as does the broad range of known impairments associated with prenatal alcohol exposure. Atypical eating behaviors related to maladaptive behaviors, physical abnormalities, sensory dysfunction, medications, and stress in caregivers were identified in preschool-aged children with FASDs by caregivers and healthcare professionals. The study findings have contributed knowledge leading to a better understanding of nutrition and eating behavior in children with FASDs, aged 3 to 5 years, and propose that the condition severity of the FASD may underlie the atypical eating behavior.

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APPENDICES

APPENDIX A

Oklahoma State University Institutional Review Board

Date: Wednesday, May 29, 2013
IRB Application No HE1343
Proposal Title: Eating Behavior in Children with Fetal Alcohol Spectrum Disorders: A Mixed Methods Study
Reviewed and Processed as: Exempt

Status Recommended by Reviewer(s): Approved Protocol Expires: 5/28/2014

Principal Investigator(s):

| | |
|--|--|
| Shirley F. Evans 301 HS Stillwater, OK 74078 | Tay Seacord Kennedy 301 HES Stillwater, OK 74078 |
|--|--|

The IRB application referenced above has been approved. It is the judgment of the reviewers that the rights and welfare of individuals who may be asked to participate in this study will be respected, and that the research will be conducted in a manner consistent with the IRB requirements as outlined in section 45 CFR 46.

The final versions of any printed recruitment, consent and assent documents bearing the IRB approval stamp are attached to this letter. These are the versions that must be used during the study.

As Principal Investigator, it is your responsibility to do the following:

1. Conduct this study exactly as it has been approved. Any modifications to the research protocol must be submitted with the appropriate signatures for IRB approval. Protocol modifications requiring approval may include changes to the title, PI, advisor, funding status or sponsor, subject population composition or size, recruitment, inclusion/exclusion criteria, research site, research procedures and consent/assent process or forms.
2. Submit a request for continuation if the study extends beyond the approval period of one calendar year. This continuation must receive IRB review and approval before the research can continue.
3. Report any adverse events to the IRB Chair promptly. Adverse events are those which are unanticipated and impact the subjects during the course of this research; and
4. Notify the IRB office in writing when your research project is complete.

Please note that approved protocols are subject to monitoring by the IRB and that the IRB office has the authority to inspect research records associated with this protocol at any time. If you have questions about the IRB procedures or need any assistance from the Board, please contact Dawnnett Watkins 219 Cordell North (phone: 405-744-5700, dawnnett.watkins@okstate.edu).

Sincerely,



Shelia Kennison, Chair
Institutional Review Board

APPENDIX B

Children’s Eating Behavior Questionnaire (CEBQ)

Please read the following statements and tick the boxes most appropriate to your child’s eating behavior.

| | Never | Rarely | Some- times | Often | Always |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| My child loves food | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| My child eats more when worried | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| My child has a big appetite | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| My child finishes his/her meal quickly | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| My child is interested in food | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| My child is always asking for a drink | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| My child refuses new foods at first | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| My child eats slowly | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| My child eats less when angry | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| My child enjoys tasting new foods | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

| | | | | | |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| My child eats less when s/he is tired | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| My child is always asking for food | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| My child eats more when annoyed | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| If allowed to, my child would eat too much | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| My child eats more when anxious | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| My child enjoys a wide variety of foods | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| My child leaves food on his/her plate at the end of a meal | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| My child takes more than 30 minutes to finish a meal | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

APPENDIX C

Table 1. Socio-demographic characteristics of caregivers, who had children with FASDs, aged 3 to 5 years old, that participated in the online survey ($n = 74$)

| | <i>n</i> (%) |
|---|--------------|
| Sex | |
| Male | 1 (2) |
| Female | 50 (98) |
| Relationship to child | |
| Biological parent | 1 (1) |
| Adoptive parent or Foster parent | 63 (85) |
| Grandparent | 9 (12) |
| Other | 1 (2) |
| Ethnicity | |
| African American | 1 (2) |
| Asian | 2 (4) |
| Hispanic | 1 (2) |
| White | 46 (90) |
| Native American including Alaskan Native | 1 (2) |
| Marital status | |
| Single, never married, Single divorced, and Single, widowed | 9 (18) |
| Married, first time | 31 (61) |
| Remarried | 11 (21) |
| Number of members per household | |
| 2 and 3 members | 13 (26) |
| 4 and 5 members | 21 (43) |
| 6, 7, and 8 members | 15 (31) |

Education

11th or 12th grade, Some Vo-tech or College classes, or Vo-tech graduate 16 (32)

College graduate 23 (46)

Postgraduate degree 11 (22)

Employment status

Unemployed, Not employed (disability), Retired, and Unknown 23 (46)

Employed Part-time 14 (28)

Employed Full-time 13 (26)

Total 2012 family income

Unknown 1 (2)

Under \$30,000 8 (16)

\$31,000 - \$75,000 20 (40)

Greater than \$75,000 21 (42)

Residence**United States**

North-east region 6 (12)

New Jersey (2), New York (3), Pennsylvania (1)

Midwest region 14 (29)

Illinois (1), Indiana (1), Michigan (3), Minnesota (7), Wisconsin (1)

West region 13 (26)

Alaska (1), Arizona (1), California (8), Colorado (1), Washington (2)

South region 14 (29)

Arkansas (2), Florida (1), Maryland (1), North Carolina (5), Texas (5)

International 2 (4)

Alberta, Canada (1), Scotland (1)

APPENDIX D

Table 2. Socio-demographic characteristics of children with FASDs, aged 3 to 5 years, as reported by the caregivers ($n = 80$)

| | <i>M±SD^a</i> |
|---|-------------------------|
| Birth weight (kg) | 2.7±0.7 |
| Boys | 2.8±0.7 |
| Girls | 2.6±0.6 |
| Z-scores: Overall, gender, and age group | |
| Weight-for-age z-score | 0.28±1.1 |
| Boys | 0.24±1.3 |
| Girls | 0.36±0.7 |
| 3-year-olds | 0.66±0.9 |
| 4-year-olds | 0.09±1.2 |
| 5-year-olds | 0.26±1.2 |
| Height-for-age z-score | 0.10±2.0 |
| Boys | -0.25±2.2 |
| Girls | 0.80±1.3 |
| 3-year-olds | 0.13±1.0 |
| 4-year-olds | -0.39±2.2 |
| 5-year-olds | 0.46±2.2 |
| BMI z-score | 0.22±1.9 |
| Boys | 0.39±2.1 |
| Girls | -0.10±1.2 |
| 3-year-olds | 0.39±1.3 |
| 4-year-olds | 0.27±2.2 |
| 5-year-olds | 0.08±1.9 |

| | n (%) |
|---|--------------|
| Sex | |
| Boys | 49 (61) |
| Girls | 31 (39) |
| Age groups | |
| 3 years | 14 (18) |
| 4 years | 30 (37) |
| 5 years | 36 (45) |
| Ethnicity | |
| African American | 9 (15) |
| Asian | 2 (3) |
| Hispanic | 8 (13) |
| White | 35 (57) |
| Native American, including Alaskan Native | 5 (8) |
| Other race | 3 (4) |
| Birth weight > 2.5 kg | 16 (40) |
| Boys | 9 (56) |
| Girls | 7 (44) |
| Birth weight ≤ 2.5 kg | 24 (60) |
| Boys | 15 (63) |
| Girls | 9 (37) |
| BMI percentile groups | |
| Underweight | 6 (16) |
| Boys | 5 (83) |
| Girls | 1 (17) |
| Normal weight | 21 (57) |

| | |
|-------------------------|---------|
| Boys | 11 (52) |
| Girls | 10 (48) |
| Overweight/obese | 10 (27) |
| Boys | 8 (80) |
| Girls | 2 (20) |

^a $M \pm SD$ = mean \pm standard deviation.

APPENDIX E

Table 3. Descriptive statistics of CEBQ subscales for all study children and by gender with independent samples *t*-tests by gender between study children with FASDs, aged 3 to 5 years, as reported by the caregivers, and a normative sample of children^a

| CEBQ Subscales | All Children with FASDs | | | Boys with FASDs | | Boys of Normative Sample ^b | | <i>p for t-test</i> | Girls with FASDs | | Girls of Normative Sample ^b | | <i>p for t-test</i> |
|------------------------|-------------------------|-------------------------|----------|-------------------------|----------|---------------------------------------|----------|---------------------|-------------------------|----------|--|----------|---------------------|
| | Cronbach's <i>α</i> | <i>M±SD^a</i> | <i>n</i> | <i>M±SD^a</i> | <i>n</i> | <i>M±SD^a</i> | <i>n</i> | | <i>M±SD^a</i> | <i>n</i> | <i>M±SD^a</i> | <i>n</i> | |
| EF^c | 0.94 | 3.2±1.1 | 69 | 3.1±1.0 | 45 | 3.6±0.8 | 215 | 0.001 | 3.4±1.3 | 24 | 3.6±0.9 | 181 | 0.443 |
| EOE^d | 0.84 | 2.1±0.9 | 68 | 2.2±1.0 | 44 | 1.8±0.6 | 215 | 0.018 | 2.1±0.9 | 24 | 1.8±0.6 | 181 | 0.112 |
| DD^e | 0.94 | 3.5±1.3 | 69 | 3.5±1.3 | 44 | 2.9±1.1 | 215 | 0.005 | 3.5±1.3 | 25 | 2.9±1.2 | 181 | 0.029 |
| FR^f | 0.93 | 2.8±1.3 | 68 | 2.7±1.2 | 44 | 2.3±0.8 | 215 | 0.044 | 3.0±1.3 | 24 | 2.2±0.8 | 181 | 0.008 |
| SR^g | 0.90 | 3.2±1.1 | 69 | 3.2±1.0 | 44 | 3.1±0.7 | 215 | 0.587 | 3.2±1.2 | 25 | 3.1±0.7 | 181 | 0.827 |
| SE^h | 0.92 | 3.4±1.2 | 67 | 3.4±1.2 | 44 | 3.1±0.8 | 215 | 0.159 | 3.4±1.3 | 23 | 3.2±0.8 | 181 | 0.554 |
| FFⁱ | 0.90 | 3.3±1.1 | 68 | 3.4±1.0 | 43 | 3.1±0.9 | 215 | 0.030 | 3.1±1.2 | 25 | 2.9±0.9 | 181 | 0.402 |
| EUE^j | 0.79 | 3.1±1.0 | 63 | 3.2±1.0 | 41 | 3.1±0.8 | 215 | 0.600 | 3.0±1.0 | 22 | 3.0±0.7 | 181 | 0.958 |

^a*M±SD* = Mean ± Standard Deviation.

^bWardle et al. (2001), page 968.

^cEF = Enjoyment of Food.

^dEOE = Emotional Overeating.

^eDD = Desire to Drink.

^fFR = Food Responsiveness.

^gSR = Satiety Responsiveness.

^hSE = Slowness in Eating.

ⁱFF = Food Fussiness.

^jEUE = Emotional Undereating.

APPENDIX F

Table 4. Descriptive statistics of the CEBQ subscales and independent *t*-tests by age between the study children with FASDs, as reported by the caregivers, and a normative sample of children^a

| CEBQ | 3-year-olds with FASDs | | 3-year-olds of Normative Sample ^a | | <i>p</i> for <i>t</i> -test | 4-year-olds with FASDs | | 4-year-olds of Normative Sample ^a | | <i>p</i> for <i>t</i> -test | 5-year-olds with FASDs | | 5-year-olds of Normative Sample ^a | | <i>p</i> for <i>t</i> -test |
|------------------------|-----------------------------------|----------|--|----------|-----------------------------|-----------------------------------|----------|--|----------|-----------------------------|-----------------------------------|----------|--|----------|-----------------------------|
| | <i>M</i> ± <i>SD</i> ^b | <i>n</i> | <i>M</i> ± <i>SD</i> ^b | <i>n</i> | | <i>M</i> ± <i>SD</i> ^b | <i>n</i> | <i>M</i> ± <i>SD</i> ^b | <i>n</i> | | <i>M</i> ± <i>SD</i> ^b | <i>n</i> | <i>M</i> ± <i>SD</i> ^b | <i>n</i> | |
| EF^c | 3.4±1.2 | 12 | 3.6±0.9 | 76 | 0.527 | 3.2±1.2 | 25 | 3.3±0.9 | 102 | 0.722 | 3.1±1.1 | 32 | 3.8±0.8 | 81 | 0.001 |
| EOE^d | 2.2±1.1 | 13 | 1.7±0.7 | 76 | 0.109 | 2.1±0.9 | 24 | 1.7±0.6 | 102 | 0.063 | 2.2±1.0 | 31 | 1.8±0.5 | 81 | 0.037 |
| DD^e | 3.7±1.1 | 13 | 3.1±1.2 | 76 | 0.082 | 3.5±1.4 | 25 | 2.9±1.1 | 102 | 0.041 | 3.4±1.3 | 31 | 3.0±1.0 | 81 | 0.136 |
| FR^f | 2.8±1.2 | 13 | 2.2±0.8 | 76 | 0.078 | 2.8±1.4 | 24 | 2.1±0.7 | 102 | 0.014 | 2.7±1.2 | 31 | 2.3±0.7 | 81 | 0.068 |
| SR^g | 3.3±1.0 | 13 | 3.2±0.5 | 76 | 0.875 | 3.2±1.1 | 24 | 3.3±0.6 | 102 | 0.753 | 3.1±1.0 | 32 | 3.0±0.7 | 81 | 0.594 |
| SE^h | 3.3±1.3 | 12 | 3.4±0.7 | 76 | 0.820 | 3.9±1.1 | 24 | 3.4±0.8 | 102 | 0.068 | 3.0±1.2 | 31 | 3.1±0.7 | 81 | 0.714 |
| FFⁱ | 3.5±0.9 | 12 | 2.9±0.8 | 76 | 0.022 | 3.2±1.1 | 25 | 3.1±0.9 | 102 | 0.785 | 3.4±1.1 | 31 | 2.9±0.9 | 81 | 0.03 |
| EUE^j | 2.8±1.0 | 11 | 3.3±0.8 | 76 | 0.143 | 3.2±1.0 | 24 | 3.1±0.8 | 102 | 0.806 | 3.2±1.0 | 28 | 3.0±0.6 | 81 | 0.258 |

^aWardle et al. (2001), page 968.

^b*M*±*SD* = means±standard deviation.

^cEF = Enjoyment of Food.

^dEOE = Emotional Overeating.

^fFR = Food Responsiveness.

^gSR = Satiety Responsiveness.

^hSE = Slowness in Eating.

¹FF = Food Fussiness.

¹EUE = Emotional Undereating.

APPENDIX G

Table 5. Pearson's product-moment correlations between socio-demographic characteristics of the caregivers and children with FASDs, aged 3 to 5 years, in the study

| | <i>n</i> | 1. | 2. | 3. | 4. | 5. | 6. | 7. | 8. | 9. | 10. | 11. | 12. | 13. |
|-------------------------------|----------|----|---------|-------|-------|--------|-------|-------|-------|-------|--------|--------|---------|--------|
| 1. Caregiver age | 45 | -- | -0.46** | 0.03 | 0.03 | -0.36* | -0.24 | 0.30 | 0.27 | -0.01 | 0.30 | 0.01 | 0.28 | 0.15 |
| 2. Household | 49 | | -- | -0.08 | -0.18 | 0.34* | 0.22 | -0.22 | 0.02 | -0.03 | -0.05 | -0.12 | 0.08 | 0.19 |
| 3. Education | 50 | | | -- | 0.15 | 0.36* | 0.10 | -0.18 | 0.04 | -0.18 | -0.11 | -0.22 | 0.16 | -0.26 |
| 4. Employment | 50 | | | | -- | 0.13 | -0.26 | 0.03 | -0.17 | -0.15 | -0.04 | -0.14 | 0.20 | -0.09 |
| 5. 2012 income | 50 | | | | | -- | 0.28* | 0.04 | -0.21 | 0.04 | -0.17 | 0.07 | -0.16 | -0.23 |
| 6. Marital status | 51 | | | | | | -- | 0.18 | -0.01 | 0.13 | 0.28 | 0.20 | -0.12 | -0.05 |
| 7. Children's age | 80 | | | | | | | -- | -0.10 | 0.11 | 0.55** | 0.59** | -0.07 | -0.01 |
| 8. WAZ ^a | 48 | | | | | | | | -- | 0.39* | 0.75** | 0.29 | -0.48** | 0.54** |
| 9. HAZ ^b | 37 | | | | | | | | | -- | 0.33* | 0.86** | 0.59** | 0.33 |
| 10. Current weight | 48 | | | | | | | | | | -- | 0.58** | 0.35* | 0.44* |
| 11. Current height | 46 | | | | | | | | | | | -- | 0.53** | 0.30 |
| 12. BMI z-score | 37 | | | | | | | | | | | | -- | 0.30 |
| 13. Birth weight ^c | 40 | | | | | | | | | | | | | -- |

*. Correlation significant at the 0.05 level (2-tailed).

** . Correlation significant at the 0.01 level (2-tailed).

^aWAZ = weight-for-age z-score.

^bHAZ = height-for-age z-scores.

^cBirthweight of study children.

Appendix H

Table 6. Pearson's product-moment correlations between CEBQ subscales and the number of members in the households of caregivers, who participated in the online survey, and birthweight of children with FASDs, aged 3 to 5 years, as reported by caregivers

| | <i>n</i> | 1. | 2. | 3. | 4. | 5. | 6. | 7. | 8. | 9. | 10. | 11. | 12. |
|------------------------------------|----------|----|--------|--------|--------|---------|---------|---------|--------|---------|---------|--------|--------|
| 1. EF^a | 69 | -- | 0.48** | 0.29* | 0.82** | -0.77** | -0.48** | -0.71** | -0.2 | 0.81** | -0.72** | 0.38* | 0.13 |
| 2. EOE^b | 68 | | -- | 0.32** | 0.62** | -0.42** | -0.29* | -0.38** | -0.07 | 0.74** | -0.40** | 0.30* | 0.33* |
| 3. DD^c | 69 | | | -- | 0.44** | -0.35** | -0.1 | -0.17 | -0.24 | -0.74** | 0.89** | 0.03 | 0.23 |
| 4. FR^d | 68 | | | | -- | -0.77** | -0.44** | -0.54** | -0.22 | -0.42** | 0.71** | 0.42** | 0.33* |
| 5. SR^e | 69 | | | | | -- | 0.57** | 0.59** | 0.52** | 0.67** | -0.26* | -0.24 | -0.25 |
| 6. SE^f | 67 | | | | | | -- | 0.35** | 0.12 | -0.56** | 0.77** | -0.21 | -0.40* |
| 7. FF^g | 68 | | | | | | | -- | 0.33* | -0.24 | 0.64** | -0.15 | 0.04 |
| 8. EUE^h | 63 | | | | | | | | -- | 0.92** | -0.70** | -0.27 | -0.05 |
| 9. FAPPⁱ | 66 | | | | | | | | | -- | -0.66** | 0.38* | 0.33* |
| 10. FAVO^j | 54 | | | | | | | | | | -- | -0.25 | -0.19 |
| 11. Household group | 47 | | | | | | | | | | | -- | 0.19 |
| 12. Birthweight^k | 40 | | | | | | | | | | | | -- |

*. Correlation significant at the 0.05 level (2-tailed).

**. Correlation significant at the 0.01 level (2-tailed).

^aEF = Enjoyment of Food

^bEOE = Emotional Overeating

^cDD = Desire to Drink

^dFR = Food Responsiveness

^eSR = Satiety Responsiveness

^fSE = Slowness in Eating

^gFF = Food Fussiness

^hEUE = Emotional Undereating

ⁱFAPP = Food Approach

^jFAVO = Food Avoidance

^kBirthweight of children

APPENDIX I

Table 1. Socio-demographic characteristics of the caregivers and children with FASDs, aged 3 to 5 years, in the study

| Caregiver Characteristics | <i>M±SD^a</i> | <i>n</i> | Percentages |
|--|--------------------------------|-----------------|--------------------|
| Age (yrs) | 42.3±8.1 | 45 | |
| Gender | | | |
| Female | | 50 | 98.0 |
| Male | | 1 | 2.0 |
| Total | | 51 | 100.0 |
| Children Characteristics | <i>M±SD^a</i> | <i>n</i> | Percentages |
| Age (yrs) | 4.2±0.8 | 59 | |
| Gender | | | |
| Girls | | 20 | 34.0 |
| Boys | | 39 | 66.0 |
| Total | | 59 | 100.0 |
| Co-occurring Diagnoses | | | |
| Yes | | 48 | 83.0 |
| No | | 10 | 17.0 |
| Total | | 58 | 100.0 |
| Number of Co-occurring Diagnoses per Child | 2.4±2.3 | | |
| Medications | | | |
| Yes | | 28 | 48.0 |
| No | | 30 | 52.0 |
| Total | | 58 | 100.0 |
| Number of Medications per Child | 1.1±1.7 | | |

^a*M±SD* = mean±standard deviation.

APPENDIX J

Table 2. Total and percentages of co-occurring diagnoses in children with FASDs, aged 3 to 5 years old, as reported by caregivers

| Co-occurring Diagnoses^a | <i>n</i> | Percentages |
|---|-----------------|--------------------|
| Total Number of Co-occurring Diagnoses | 136 | 100.0 |
| Physical Anomalies | 8 | 5.9 |
| Hypospadias | | |
| Growth Issues | | |
| Failure To Thrive | | |
| Acrocyanosis | | |
| Enlarged Adenoids | | |
| Frail Body | | |
| Hypermobility | | |
| Organ System Dysfunction | 21 | 15.4 |
| Gastrointestinal | | |
| Delayed Gastric Emptying | | |
| Acid Reflux | | |
| Feeding Issues | | |
| Chronic Constipation | | |
| G-Tube | | |
| Gluten Issues | | |
| Necrotizing Enterocolitis | | |
| Cardiac | | |
| Pre-Ventricular Contraction | | |
| Premature Junction Beat | | |
| Skin | | |
| Hypohydrotic Ectodermal Dysplasia | | |
| Eczema | | |
| Pulmonary | | |
| Bronchopulmonary Dysplasia | | |
| Renal | | |
| Single Kidney | | |
| Hepatic | | |
| Liver Issues | | |
| Psychiatric Disorders | 36 | 26.5 |
| Attention Deficit Hyperactivity Disorder (n = 18) | | |
| Autism Spectrum Disorder (n = 5) | | |
| Reactive Attachment Disorder (n = 5) | | |
| Posttraumatic Stress Disorder | | |
| Oppositional Defiant Disorder | | |
| Bipolar Disorder | | |
| Hyperkinetic | | |
| Impulsive | | |
| Pica | | |
| Low IQ | | |
| Sensory | 20 | 14.7 |
| Vision Impairment | | |

| | | |
|--------------------------------------|----|------|
| Septo-optic dysplasia | | |
| Sensory Processing Disorder (n = 13) | | |
| Auditory Processing Deficits | | |
| Visual Processing Deficits | | |
| Speech Sound Disorder | | |
| Neurological Disorders | 15 | 11.0 |
| Cerebral Palsy | | |
| Microcephaly | | |
| Abnormal EEG | | |
| Cognitive Processing Deficits | | |
| Encephalopathy | | |
| Organic Brain Damage | | |
| Neurohypophysis | | |
| Ataxia ^b | | |
| Partial Complex Seizures | | |
| Dyspraxia | | |
| Verbal Apraxia | | |
| Oral Motor Dyspraxia | | |
| Dysarthritic | | |
| Developmental | 9 | 6.6 |
| General Delays | | |
| Major Speech/Language Delay | | |
| Social Emotional Delay | | |
| Learning Disabled | | |
| Allergies | 7 | 5.1 |
| Asthma | | |
| Food Allergies | | |
| Milk Intolerance | | |
| Motor | 3 | 2.2 |
| Ptosis of Left Eye | | |
| Low Motor Tone | | |
| Motor Apraxia | | |
| Dyspraxia | | |
| Other | 17 | 12.5 |
| Lack of Coordination | | |
| Mood Disorder (non-specified) | | |
| Childhood trauma/abuse | | |
| Anxiety Disorder (non-specified) | | |
| Explosive Personality | | |
| Processing Disorder | | |
| Fetal Depakote Syndrome | | |
| Prenatal Cocaine Exposure | | |
| Klippel Feil Syndrome | | |
| Sprengel's Deformity | | |
| Sleep Disturbance | | |

Sleep Apnea
Ear Infections
Hip Problems
Webbed Neck
Genetic Syndrome

^aCo-occurring diagnoses were often greater than 1 per child and reported verbatim by caregivers. Some may not be specifically defined in the DSM-IV and were not professionally confirmed. Frequency for each type of diagnosis is not listed due to many diagnoses being only reported once.

APPENDIX K

Table 3. Total, percentages, and associated nutrient-related side effects of medications taken by the children with FASDs, aged 3 to 5 years, as reported by caregivers

| Medications ^a | <i>n</i> | Percentage | Nutrition-related Side Effects ^{bc} |
|--|----------|------------|---|
| Total Number of Medications | 66 | 100 | |
| Psychiatric | 37 | 56.0 | |
| Aripiprazole | | | Increased Weight/Obesity Increased or decreased salivation Dry Mouth Nausea/Vomiting Dyspepsia/Abdominal pain Constipation or Diarrhea |
| Atomoxetine HCl | | | Decreased appetite/Decreased weight Delayed Growth in Children Dry Mouth Nausea/Vomiting Dyspepsia/Abdominal pain Constipation or Diarrhea |
| Clonidine | | | Increased Weight due to edema Anorexia Dry Mouth Nausea/Vomiting Constipation |
| Detromethylphenidate | | | Decreased Growth with Long Term Use |
| Dextroamphetamine Sulf-Saccharate/Amphetamine Sulf-Aspartate | | | Dry Throat |
| Fluoxetine | | | Nausea Anorexia Abdominal Pain |
| Guanfacine | | | Increased Weight Due to Edema Anorexia Dry Mouth Nausea/Vomiting Constipation |
| Imipramine | | | Weight gain or loss |
| Lamotrigine | | | Anorexia/Decreased weight Nausea/Vomiting Dyspepsia/Abdominal pain Constipation or Diarrhea |
| Lisdexamfetamine | | | Decreased weight |
| Methylphenidate Slow Release | | | Anorexia |
| Oxcarbazepine | | | Hyponatremia |
| Risperidone | | | Increased appetite |
| Sertraline | | | Decreased appetite |
| Trazodone hydrochloride | | | Taste Changes Dyspepsia |

| | | | |
|-------------------------------------|----|------|---|
| | | | Nausea/Vomiting Constipation or Diarrhea Increased appetite/Increased or decreased weight Dry Mouth |
| Asthma/Allergies | 13 | 20.0 | |
| Albuterol Sulfate Nebulizer | | | Peculiar Taste Dyspepsia Diarrhea Increased Appetite or Anorexia Nausea/Vomiting Increase weight Increased appetite Dry Mouth Nausea/Vomiting Constipation or Diarrhea Increased thirst Decreased sense of taste Nausea/Vomiting Dyspepsia |
| Cetirizine | | | |
| Cyproheptadine | | | |
| Fluticasone Furoate | | | |
| Loratadine | | | |
| Mometasone | | | |
| Montelukast Sodium | | | |
| Gastrointestinal Medications | 7 | 10.0 | |
| Fiber Supplements | | | Vomiting Diarrhea/Cramping Dry Mouth Decrease absorption of Iron and vitamin B12 Nausea Abdominal Pain Diarrhea Bitter Taste Nausea Abdominal Pain Constipation or Diarrhea Nausea |
| Hydroxyzine | | | |
| Omeprazole Magnesium | | | |
| Ondansetron | | | |
| Polyethylene Glycol | | | |
| Other | 3 | 5.0 | |
| Pimecrolimus Cream | | | Fever, Chills Nausea/Vomiting Diarrhea |
| Antibiotics | | | |
| Nutrition Supplements | 6 | 9.0 | |
| Melatonin | | | Abdominal Discomfort Nausea Constipation Abdominal Pain/Belching |
| Multivitamins | | | |
| Ferrous Sulfate | | | |
| Fish Oil | | | |

^aSome medications are used in treatment of other conditions, such as clonidine for hypertension. Some children received more than one medication. The medications were reported verbatim by the caregivers and not professionally confirmed. Frequency of each individual medication was not listed since some medications were only given to one child.

^bOzsfarati J, Koren G. Medications used in the treatment of disruptive behavior in children with FASD--a guide. *J Popul Ther Clin Pharmacol*. 2015; 22(1):e59-67.

^cPronsky ZM. *Food-Medication Interactions*TM 14th ed. Birchrunville, PA: Food-Medication InteractionsTM, 2006.

APPENDIX L

Table 4. Descriptive statistics and Cronbach's α of CEBQ Subscales for children with FASDs, aged 3 to 5 years, as reported by caregivers

| CEBQ Subscale | Cronbach's α | $M \pm SD^a$ | n |
|------------------------|---------------------------------------|--------------------------------|-----------------------|
| Food Approach | | 2.8 \pm 0.9 | 54 |
| Enjoyment of Food | 0.91 | 3.0 \pm 1.1 | 57 |
| Food Responsiveness | 0.80 | 2.7 \pm 1.3 | 56 |
| Desire to Drink | 0.89 | 3.4 \pm 1.3 | 57 |
| Emotional Overeating | 0.79 | 2.1 \pm 1.0 | 56 |
| Food Avoidance | | 3.4 \pm 0.8 | 47 |
| Food Fussiness | 0.91 | 3.5 \pm 1.1 | 56 |
| Slowness in Eating | 0.74 | 3.5 \pm 1.2 | 55 |
| Satiety Responsiveness | 0.74 | 3.3 \pm 1.1 | 57 |
| Emotional Undereating | 0.74 | 3.1 \pm 1.0 | 53 |

^a $M \pm SD$ = Mean plus or minus Standard deviation.

APPENDIX M

Table 5. Descriptive statistics for CBCL/1.5-5 Total Raw Scores, *T* Scores, and clinical range for syndrome, broad scales and DSM-oriented scales in children with FASDs, aged 3 to 5 years, as reported by caregivers

| | | | | | Percentage of Clinical Ranges for All Children based on mean <i>T</i> scores ^e | | | |
|-------------------------|---------------------|--------------|--------------|----------------|---|-----------------|------------|----------|
| | | | | | Total Raw Scores | <i>T</i> Scores | Borderline | Clinical |
| Scales | Cronbach's α | $M \pm SD^a$ | $M \pm SD^a$ | Range | % (n) | % (n) | | |
| Syndrome Scales | | | | | | | | |
| Emotionally Reactive | 0.76 | 8.32±4.5 | 70.05±12.8 | C ^d | 23.7(14) | 47.5(28) | | |
| Anxious Depressed | 0.74 | 6.39±3.5 | 64.10±10.6 | N ^b | 25.4(15) | 27.1(16) | | |
| Somatic Complaints | 0.65 | 5.92±3.4 | 65.92±9.1 | B ^c | 27.1(16) | 37.3(22) | | |
| Withdrawn | 0.78 | 5.92±3.3 | 69.20±10.5 | B ^c | 13.6(8) | 52.5(31) | | |
| Sleep Problems | 0.78 | 6.42±3.7 | 65.12±13.2 | B ^c | 6.8(4) | 32.2(19) | | |
| Attention Problems | 0.78 | 6.85±2.7 | 69.31±9.1 | B ^c | 5.1(3) | 67.8(40) | | |
| Aggressive Problems | 0.94 | 21.02±9.5 | 67.86±13.5 | B ^c | 18.6(11) | 42.4(25) | | |
| Broadband Scales | | | | | | | | |
| Internalizing Problems | 0.82 | 26.54±11.4 | 69.32±10.2 | C ^d | 10.2(6) | 72.9(43) | | |
| Externalizing Problems | 0.94 | 27.86±11.4 | 67.83±14.2 | C ^d | 8.5(5) | 66.1(39) | | |

| | | | | | | |
|--|------|------------|------------|----------------|---------|----------|
| Total Problems | 0.96 | 85.32±32.7 | 71.69±12.8 | C ^d | 11.9(7) | 76.3(45) |
| DSM^f-oriented Scales | | | | | | |
| Stress Problems | | 6.10±2.7 | 70.31±10.6 | C ^d | 10.2(6) | 61.0(36) |
| Depressive Problems | | 8.03±4.1 | 71.17±10.9 | C ^d | 5.1(3) | 61.0(36) |
| Anxiety Problems | | 9.42±4.2 | 70.49±12.4 | C ^d | 3.4(2) | 62.7(37) |
| Autism Spectrum Problems | | 9.03±4.6 | 70.52±11.0 | C ^d | 13.6(8) | 67.8(40) |
| Attention Deficit Hyperactivity Problems | | 9.14±3.0 | 65.78±8.1 | B ^c | 6.8(4) | 42.4(25) |
| Oppositional Defiant Problems | | 6.66±3.8 | 63.56±10.7 | N ^b | 0(0) | 37.3(22) |

^a $M \pm SD$ = Mean plus or minus Standard deviation.

^bN = normal range.

^cB = borderline clinical range.

^dC = Clinical range.

^ePercentage of children in the normal range for each scale is determined by $100 - (\text{Borderline} + \text{Clinical range})$.

^fDSM = Diagnostic and Statistical Manual.

APPENDIX N

Table 6. Multiple linear regression with backward elimination between the CEBQ subscales, CBCL/1.5-5 scales, and total number of medications in children with FASDs, aged 3 to 5 years, as reported by the caregivers

| Dependent Variables | <i>n</i> | Independent Variables | | | | | |
|-----------------------|----------|--------------------------------------|----------|--------------------------------------|----------|--|----------|
| | | Internalizing Problems ^{ac} | | Externalizing Problems ^{ac} | | Medications and Somatic Complaints ^{bc} | |
| CEBQ Subscales | <i>n</i> | <i>R</i> ² | <i>p</i> | <i>R</i> ² | <i>p</i> | <i>R</i> ² | <i>p</i> |
| Slowness in Eating | 55 | | | | | 0.271 | 0.000 |
| Food Fussiness | 56 | 0.081 | 0.034 | | | | |
| Emotional Undereating | 53 | 0.087 | 0.032 | | | | |
| Emotional Overeating | 56 | | | 0.115 | 0.011 | | |
| | | | | | | | |

^aMultiple linear regression with model 1.

^bMultiple linear regression with model 2.

^cMultiple linear regression criteria for probability of *F*: Entry of 0.05 and removal of 0.10.

APPENDIX O

Table 1. Topic guide of focus group questions for healthcare professionals regarding eating behavior in children with FASDs, aged 3 to 5 years

- If I visited your office/clinic, what would be a typical day in providing care to a child with FASD?
 - Would you please describe your most memorable experience in caring for a child with FASD?
 - When caring for children with FASD, what is your understanding of their nutritional status?
 - In relation to nutrition, how would you perceive that the disabilities associated with FASD-might or might not influence the children's eating?
 - If children with FASD have eating problems, how do you think your profession might or might not care for these problems?
 - Overall, what are your views regarding the eating behavior of children with FASD?
-

APPENDIX P

Table 2. Socio-demographic characteristics of healthcare professionals in the focus groups (n = 26)

| Variables | % (n) |
|--|-----------|
| Profession | |
| Physician, Physician Assistant, and Nurse Practitioner | 22.8 (6) |
| Psychologist | 11.5 (3) |
| Occupational Therapist | 7.7 (2) |
| Speech Language Pathologist | 7.7 (2) |
| Social Worker | 7.7 (2) |
| Licensed Professional Counselor | 15.2 (4) |
| FASD parent counselors | 7.7 (2) |
| Dietitian | 3.8 (1) |
| Other | 11.4 (3) |
| Researcher, International FASD organization Board Member, Project Coordinator for Parent Child Interaction Therapy | |
| Type of practice (select all that apply) | |
| Solo | 9.5 (2) |
| Group | 9.5 (2) |
| Community | 24.0 (5) |
| Faculty | 38.0 (8) |
| Other | 19.0 (4) |
| Practice (select all that apply) | |
| Rural | 19.2 (5) |
| Suburban | 38.5 (10) |
| Urban/Inner City | 42.3 (11) |
| Urban/Not Inner City | 34.6 (9) |
| Other | 7.7 (2) |
| Location of practice (select all that apply) | |
| United States | |
| Colorado | 3.8 (1) |
| Kansas | 15.4 (4) |
| Maine | 3.8 (1) |
| Maryland | 3.8 (1) |
| Minnesota | 15.4 (4) |
| Missouri | 7.7 (2) |
| Nebraska | 3.8 (1) |
| Oklahoma | 30.8 (9) |
| Oregon | 3.8 (1) |
| Wisconsin | 3.8 (1) |
| International location of practice | |
| Netherlands | 3.8 (1) |

APPENDIX Q

Table 3. Socio-demographic characteristics of children with FASDs, aged 3 to 5 years, under the care of the healthcare professionals in the focus groups

| | % (<i>n</i>) |
|--|----------------|
| Ethnicity of children | |
| African American | 61.5 (16) |
| Asian | 30.8 (8) |
| Hispanic | 38.5 (10) |
| Native Hawaiian/Other | 26.9 (7) |
| Caucasian | 76.9 (20) |
| Native American/Alaskan | 7.7 (2) |
| Socio-economic level of children (select all that apply) | |
| Low | 61.5 (16) |
| Middle | 73.1 (19) |
| High | 46.2 (12) |
| Unknown | 15.4 (4) |
| Caregiver's relationship to children | |
| Biological | 42.3 (11) |
| Adoptive | 76.9 (20) |
| Foster | 61.5 (16) |
| Other (grandparents | 3.8 (1) |
| Unknown | 3.8 (1) |

VITA

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