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The quality of life of children with Fetal Alcohol Spectrum Disorders and/or prenatal alcohol exposure and the impact of the disability on families and caregivers

by

Kennedy Ann Denys

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Dedication

This research is dedicated to every individual who has been impacted by Fetal Alcohol Spectrum Disorders or prenatal alcohol exposure.

"We have to improve life, not just for those who have the most skills and those who know how to manipulate the system. But also for and with those who often have so much to give but never get the opportunity."
Dorothy Height

Abstract

There is little research on the quality of life of children prenatally exposed to alcohol or the impact on families and caregivers. Participants (aged 6 - 16) included 39 children with Fetal Alcohol Spectrum Disorders (FASD), 21 with prenatal alcohol exposure (PAE, not qualifying for an FASD diagnosis), and 29 typically developing controls. Children and caregivers completed the Pediatric Quality of Life Inventory (PedsQL), measuring the child's quality of life, and caregivers completed the Generic Lifestyle Assessment Questionnaire (LAQ-G), measuring the impact of childhood disability on the family. Children with FASD and PAE had significantly lower ratings of quality of life and a higher impact on the family than the controls in most areas, but the two groups did not differ significantly from each other. These findings show that both FASD and PAE negatively impact quality of life and have measurable impacts on families and caregivers.

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Introduction

Children and adolescents with Fetal Alcohol Spectrum Disorders (FASD) and/or prenatal alcohol exposure (PAE) experience a number of impairments that impact many areas of their lives and their families. The quality of life of these individuals and the impact of their disability on their caregivers and families are areas that have been largely ignored in the literature. The aims of this study were to evaluate the impact of FASD and PAE on several areas of quality of life, including social, school, emotional, physical, and cognitive functioning, and to measure the impact of the disability on the families of affected individuals.

FASD and PAE

FASD refers to individuals who have physical, mental, behavioral, and learning disabilities as a result of maternal alcohol consumption (Chudley et al., 2005). The term FASD is not a diagnostic term, but rather an umbrella term that refers to the spectrum of effects of prenatal alcohol exposure (Chudley et al., 2005). The diagnostic assessment for FASD involves assessing four main areas: confirmation of prenatal alcohol exposure; prenatal and/or postnatal growth deficiency, central nervous system (CNS) dysfunction, and a characteristic pattern of facial anomalies (Astley, 2000; Chudley et al., 2005; Riley, Infante, & Warren, 2011). Two of these four criteria (confirmation of prenatal alcohol exposure, and CNS dysfunction) must be met for a diagnosis that falls on the FASD spectrum. Diagnoses included on the FASD continuum are: Fetal Alcohol

Syndrome (FAS), partial FAS (pFAS), Static Encephalopathy/Alcohol Exposed (SE/AE), and Neurobehavioral Disorder/Alcohol Exposed (ND/AE), with FAS requiring full facial and growth effects in addition to prenatal alcohol exposure and CNS dysfunction. The term PAE is typically used to refer to individuals who were exposed to alcohol prenatally, but it does not differentiate between those who qualify for or receive a diagnosis on the FASD spectrum, and those who do not. For example, all individuals with an FASD diagnoses have PAE, but not all individuals with PAE will qualify for a diagnosis on the FASD spectrum. In this study, the term PAE is used to describe a group of individuals who were prenatally exposed to alcohol and assessed but *did not* meet the criteria for a diagnosis on the FASD spectrum. The term FASD in this study refers to a group of individual who have a diagnosis that falls on the FASD spectrum. Making the differentiation between these two groups is important because many individuals with PAE who do not qualify for a clinical diagnosis still have impairments in several areas but may have difficulty accessing supports and services that could improve their lives. Streissguth and Kanter (2004) identified having a diagnosis of FAS as being a protective factor, and having prenatal exposure to alcohol but not having the full physical features or a diagnosis of FAS as a risk factor for having higher rates of adverse outcomes. Individuals with FASD diagnoses may actually experience better outcomes due to having better access to services, supports, and early interventions, despite being more severely impaired.

In Canada, FASD occurs in 9/1000 births, making it one of the most common known causes of cognitive disability (Chudley et al., 2005), and the most common *preventable* developmental disability (Public Health Agency of Canada, 2012). A recent review by Riley et al. (2011) found that US studies have estimated the prevalence of FASD at being between 0.2/1000 to 2-5/100 and FAS between 0.5 and 7/1000. The cost of FASD in Canada is estimated at $21,642 annually at the individual level, and $5.3 billion per year for all individuals from birth to 53-years-old (Stade et al., 2009).

Primary and Secondary Disabilities

Individuals with FASD display many neurobehavioral impairments, which are brain injuries that directly result from prenatal alcohol exposure. These primary disabilities include deficits in executive functioning, processing speed and visual-spatial abilities, delayed language and motor development, diminished intellectual function, poor academic achievement, as well as difficulties with attention, learning, and memory (Kodituwakku, 2007; Mattson, Crocker, & Nguyen, 2011; Riley et al., 2011; Riley & McGee, 2005). Often individuals with FASD have average performance on simple tasks, but have more difficulty on complex tasks that require greater involvement of executive function and processing of complex information (Kodituwakku, 2007). The impairments associated with FASD are persistent over the lifespan and some may even worsen with age (see Rasmussen, Andrew, Zwaigenbaum, & Tough, 2008 for review).

Secondary disabilities are the result of the interaction between the primary disabilities of FASD and the environment. Streissguth, Barr, Kogan, & Bookstein (1996) identified several secondary disabilities common to FASD including: problems in school, trouble with the law, mental health issues, confinement, drug and alcohol abuse, and inappropriate sexual behaviours. It is the secondary disabilities of FASD that have a significant financial impact on individuals and their families, as well as the provincial and federal governments. Individuals with FASD require extensive supports and services related to health, social services, education, justice, and addictions (Jirikowic, Gelo, & Astley, 2010). Because the primary and secondary disabilities of FASD do not diminish with age, affected individuals require these supports and services through their lifetimes (Streissguth et al., 1996).

Individuals with prenatal alcohol exposure are often subject to adverse life experiences and negative environmental factors. Several studies have shown that children who are prenatally exposed to alcohol experience a high degree of family upheaval, and many are subject to multiple foster home placements (see Roberts & Nansen, 2000 for review). The foster care population has been found to be at high risk for FASD, with rates as high as 10-15 times the general population (Astley, Stachowiak, Clarren, & Clausen, 2002). Individuals with FASD and PAE have high rates of experiences of abuse, high rates of mental health issues, and often experience transient home placements (Denys, Rasmussen, & Henneveld, 2011; Pei, Denys, Hughes, & Rasmussen, 2011; Streissguth et al., 2004). In a review by Olson, Oti, Gelo, and Beck (2009), the authors observe that individuals with FASD also experience very high rates of environmental risk factors, leading to what the authors term ‘double jeopardy’ due to the poor caregiving environments that exacerbate the negative effects of prenatal alcohol exposure, placing affected individuals at further risk.

Quality of Life

Interest in children’s quality of life gained momentum in the 1980s (Eiser & Morse, 2001), motivated by the changing epidemiology of childhood disease and the treatment and care of children with chronic, or lifelong conditions or disabilities (Eiser & Morse, 2001; Chen & Cisler, 2011). Definitions of quality of life vary, however the concept of health-related quality of life tends to focus on the extent to which health status inhibits normal functioning in various areas (Stade et al., 2005), including: physical, mental, social, emotional, and behavioural functioning (Chen & Cisler, 2011). In a review of quality of life measures, Eiser and Morse (2001) state that measures of quality of life “*are the ‘gold standards’ against which all other health outcomes must be assessed. Both clinical decisions and the conduct of research can only be assisted by the development of good measures of [quality of life] in childhood*.” Interestingly, there is no ‘gold standard’ for measuring quality of life. A review by Eiser and Morse (2001) found 43 academic papers, each focused on the development of a new measure of quality of life, each with its own age range, number of items, number of domains, or type of domains being measured. Some of the measures were general, while others were disease or condition-specific. Because quality of life is subjective and personal, most of the quality of life measures found by Eiser and Morse (2001) included a self-report, and many also had a caregiver proxy report.

There are many reasons for measuring quality of life in children, including epidemiology of chronic disease, comparing outcomes in clinical trials, assessing the outcomes of new treatments, palliative care, and evaluating interventions (Eiser & Morse, 2001). Evaluating interventions is an extremely important reason to measure quality of life in the field of FASD. There are many different types of interventions being done to improve the lives of children with FASD and their caregivers; however, most of these interventions are based on expert opinion and clinical research, as there is currently very little systematic intervention research available in this area (Olson, 2009), and none of these studies include measures of quality of life. As Eiser and Morse (2001) point out, even where increases in IQ or academic attainments cannot be achieved, it may be possible to improve different aspects such as self-esteem or social functioning through interventions, thus improving quality of life. The motivation behind any intervention or service is essentially to improve the quality of life of the affected individual, yet quality of life is not commonly measured in FASD intervention research, or even in the general field of FASD.

The primary and secondary disabilities of FASD have a significant impact on the quality of life of affected individuals, however, as previously mentioned, this is an area largely ignored in the literature. Stade, Stevens, Ungar, Beyene, and Koren (2006) conducted the only published study on quality of life among children with FASD (aged 8-21 years, n =126). Stade and colleagues (2006) used the Utilities Index Mark 3 (HUI3), which measures vision, speech, hearing, dexterity, ambulation, cognition, pain and emotion, to measure the Health-Related Quality of Life (HRQL). HRQL is a sub-category of quality of life that measures health outcomes by evaluating the individual's physical, emotional, and psychosocial well-being (Fayers & Machin, 2007). In this study, the HUI3 was administered in an interview format with FASD affected children and their caregivers, and questions were asked to reflect the child's "usual" health status, not limited to any specific period of time.

The results of the study showed that children and youth with FASD have significantly lower HRQL than their typically developing Canadian counterparts. Participants with FAS had significantly lower cognitive functioning than participants with Fetal Alcohol Effects (FAE: a general term for pFAS, SE:AE, and NBD:AE), however the two groups were comparable in caregiver reports of behavioral problems, and had minimal differences in hearing, emotion, speech, and cognition, and no differences in vision, dexterity, pain, or ambulation. Children rated their HRQL somewhat higher than their caregivers rated it, however the authors do not state whether this difference is statistically significant. There were, however, strong correlations between child and caregiver HRQL scores (Stade et al., 2006). The participants were rated as having moderate to severe dysfunction on the HUI3 in the areas of cognition and emotion. Additionally, the participants' HRQL scores were extremely low even compared to children (in other published studies) living with other disabilities or illnesses including significant physical disabilities (blindness, cerebral palsy, deafness, cognitive impairment), and childhood cancers (Stade et al., 2006).

Stade and colleagues (2006) suggest that increasing HRQL could decrease negative emotional feelings that children and adolescents with FASD feel as a result of their disability and that programs should be developed with HRQL in mind. A limitation of this study is that the sample was collected through Canadian parent support groups; children whose parents are engaged in FASD support groups may have generally higher quality of life as their families are more engaged in the community and trying to meet their child's needs. A more general sample of the Canadian FASD population is needed to increase the external validity. An additional limitation of this study is that the HRQL results from the FASD participants were compared to reference group data from the National Longitudinal Health Survey of Children (NLSC), and not their own collected control group. Results were also compared to those of children with other disabilities, but this data was obtained from previous publications on HRQL scores of low birth weight children and children living with childhood cancers. The 2006 study by Stade and colleagues is a milestone in FASD research as it is the first study to directly measure quality of life. The present study is extremely important in the field of FASD, as there are no published studies to date comparing quality of life scores of children with FASD with children with PAE as well as an independently recruited control group.

Impact on Families and Caregivers

Caregivers of individuals with FASD face unique challenges and issues, and the primary and secondary disabilities associated with FASD can have a negative effect on the family of the affected individual (Brown & Bednar, 2003). Caring for an individual with FASD can be taxing for families and caregivers who may struggle with discrepancies between age-appropriate expectations of the child, and his or her actual functional abilities (Olson et al., 2009).

There are very few studies directly examining the impact of raising a child with FASD or PAE on the caregivers or the family. However, one study by Paley, O'Connor, Kogan, and Findlay (2005) found correlations between maternal stress and externalizing behaviours of children who were prenatally exposed to alcohol. Children with different levels of prenatal alcohol exposure were divided into two groups: abstinent-light and moderate-heavy maternal drinking; none of the children met full criteria for FAS (Paley et al., 2005), however it is possible that some may have qualified for other diagnoses on the FASD spectrum. Behaviours of the children were rated by caregivers using the Externalizing Behavior Scale from the Child Behavior Checklist (CBCL), and parental stress was measured using the Parental Stress Index (PSI), which gives a Total Stress score, and then divides into three domain scores: Parent Stress (stress related to parental characteristics), Child Stress (stress related to child characteristics), and Life

Stress (stress related to situational circumstances, often beyond the parent's control). Maternal alcohol use during pregnancy was significantly correlated with child externalizing behavior, with children in the moderate-heavy maternal drinking group having significantly higher scores than children in the abstinent-light group (Paley et al., 2005). The Child, Parent, and Total Stress scores on the PSI were significantly correlated with child externalizing problems, however the Life Stress score was not (Paley et al., 2005). Child externalizing behaviour and maternal stress were not correlated with any of the following covariates: child IQ, gender, ethnicity, maternal SES, maternal IQ, marital status, years of education, total number of adults living in the home, number of children living in the home, and total number of the child's siblings living in the home (Paley et al., 2005). The results of this study demonstrate that parents of children with moderate to heavy levels of prenatal alcohol exposure may experience significantly higher levels of stress than parents of non- or lightly-exposed children, due to the children exhibiting higher levels of externalizing behaviour. The relationship between child externalizing behaviours and parental stress is likely reciprocal and part of a self-perpetuating cycle, with maternal stress impacting children who in turn exhibit higher levels of externalizing behaviours, and these behaviours causing higher levels of parental stress (Paley et al., 2005).

A second study using the PSI (Paley, O'Connor, Frankel & Marquardt, 2006) looked at 100 children who had diagnoses on the FASD spectrum (11% FAS; 43% pFAS; 46% SE/AE) and their caregivers (23% bio; 71% adoptive; 6%

foster in process of adopting). In addition to the PSI, this study included IQ, measures of executive functioning and adaptive functioning as rated by the caregiver, a family resources scale, and teacher ratings of internalizing and externalizing behaviours of the child as well as academic performance and adaptive functioning. Child Stress as rated by the caregivers on the PSI was significantly associated with higher levels of externalizing and internalizing behaviour of the child, and poorer executive and adaptive functioning.

Adoptive and foster parents also reported higher levels of Child Stress than biological parents. Interestingly, there were no associations found between diagnosis or IQ, and Child Stress; having a diagnosis of FAS was not related to caregivers reporting higher levels of stress compared to caregivers of children with other diagnoses on the FASD spectrum. Biological parent status and report of fewer family resources were the significant predictors on the PSI Parent Stress domain. This finding is important because it shows a profile of impact of child behaviours, not just that caregivers were reporting overall higher levels of stress in every domain. The authors note that a similar pattern of results were obtained from both teacher and caregiver ratings of the children, suggesting that the correlations found in this study between ratings of child behaviour and child-related stress are not a symptom of over-stressed caregivers viewing their children more negatively (Paley et al., 2006). The authors of this study stress the importance of interventions and supports not only for FASD affected children, but for their caregivers and families as well.

Parental stress can lead to many problems, including marital breakdown, physical and mental health issues, and poor parenting; thus there is a great importance in examining the impacts of FASD and PAE on the family. Providing much needed supports and resources for families and caregivers of individuals with FASD or PAE may help to ameliorate some of the negative impacts on the caregiver, the family, and the affected child. One study by Leenaars, Denys, Henneveld, and Rasmussen (2012) examined the efficacy of a family intervention program for caregivers of children with FASD. The Coaching Families Program is a mentor-based family intervention program that assists families raising one or more children with FASD through education, advocacy, support, and referrals. Leenaars et al. (2012), found that for 186 families who had completed the program there was an overall reduction in self-rated caregiver stress from pre- to post-program, as well as significant reductions in needs and an increase in goal achievement. This study stresses the importance of interventions and services for families and caregivers of children with FASD.

Support and resources for families with children or adolescents with FASD are critical (Streissguth, 1997; Streissguth & O'Malley, 2000; Chudley et al., 2005, Olson et al., 2009). Needs of families raising individuals with FASD include: information on the disability, caring and understanding clinicians, respite care, advocacy, support and resources targeted toward individual needs, opportunities to share their experiences, a greater understanding of FASD by others, and interventions and parenting supports during especially difficult developmental periods (e.g. early elementary school, transition to middle school, transition to early adulthood) (Chudley et al., 2005; Streissguth, 1997, Olson et al., 2009). It is often noted that parent support groups are helpful for caregivers of children with FASD (see Olson et al., 2009 for review). Biological, foster, and adoptive parents can all benefit from having a support network of other caregivers of children with FASD with whom they can share ideas and solutions, as well as work together to advocate and help educate professionals and the community on FASD (Streissguth, 1997).

Much of the literature on needs of caregivers of individuals with FASD is qualitative or anecdotal. In a study by Brown and Bednar (2004), nineteen caregivers of children with FASD were asked about the challenges they experience parenting a child with FASD. The results were grouped into eight clusters, each identifying a unique challenge identified by the caregivers: preventing setbacks, making time for themselves, keeping plans, home-school collaboration, keeping the child involved, lack of support, social isolation, and behaviour problems (Brown & Bednar, 2004). In discussing the concept of preventing setbacks, caregivers related that they felt challenged specifically in the areas of anticipating the child’s behaviour in new or different contexts, as well as attempting to predict and prevent problems (Brown & Bednar, 2004). Qualitative research is extremely important in connecting with caregivers and identifying their needs, the challenges they experience, and the types of support they would find most beneficial.

Due to the unique challenges of parenting and caring for an individual with FASD, families and caregivers have unique needs, including education on the disability, respite, advocacy from professionals, and support and understanding from the community (Brown & Bednar, 2004; Giutna & Stressiguth, 1998). Giutna and Streissguth (1988) identify several needs of caretakers of children with FASD, including: information, support groups, financial assistance, respite, and advocates. Information is crucial for caregivers, as it ensures that they have an understanding of the child's disability, and realistic expectations of the child's level of functioning. Support groups specific to caregivers of children with FASD or other developmental disabilities help caregivers educate and support each other and share information about caring for their children. Specialized medical and educational needs may place additional financial burdens on caregivers of children with FASD, so financial support is often essential. It is also important for caregivers to have access to respite in order to recover from the high levels of caregiver stress they may be experiencing. Lastly, advocacy from professionals is often helpful, as many caregivers are unsure of how to effectively advocate for the needs of the children they are caring for (Giutna & Streissguth, 1998). Support in these areas can help caretakers avoid burnout that is often associated with parenting children with disabilities.

Foster parents of children with FASD may have unique needs compared to adoptive and biological caregivers. In a study by Brown, Sigvaldason, and

Bednar (2005), a sample of 63 Canadian foster parents identified similar needs to those found by Giutna and Streissguth (1998), including support, respite, information, and advocacy from professionals. Additional needs identified by foster parents include personality characteristics, recognition of their experience, and specialized training. The participants identified specific personality characteristics and parenting styles that they felt were more conducive to parenting a child with FASD, which included include: calmness, confidence, and stability, as well as being able to provide structure and predictability. Foster parents have particular needs for empowerment and recognition, due to fact that they are not the child's legal guardian, but are still the day-to-day caregivers of children who have specialized needs and challenging behaviours (Brown et al., 2005). In addition to training foster parents in more general areas such as child development and the child welfare system, foster parents of children with FASD benefit from specialized training related to disabilities (Brown et al., 2005). Streissguth (1997) also identified that early knowledge of the disability is essential for foster and adoptive parents, to allow them to try to mitigate the effects of early trauma that the child may have, as well as to help them adjust their expectations of the child and identify their strengths early on.

A stable, loving home may help to reduce the risk of secondary disabilities associated with FASD, and supporting and meeting the needs of families with a child with FASD can help to support this family system

(Streissguth, 1997). A review of literature on FASD and the family by Olson et al. (2009) found that interventions aimed at increasing parent knowledge of FASD, changing parenting attitudes and behaviour, and increasing parenting skills were successful in altering caregiver attitudes and behaviours and creating positive changes in child outcomes. In order to provide appropriate services and resources for Canadian families of children with FASD or PAE a more detailed understanding of the specific impacts of FASD and PAE on the various facets of daily living is required.

Research Questions and Hypotheses

How is the quality of life of children with FASD or PAE affected compared to typically developing control children? Do FASD and PAE have an impact on the family? Is there a relationship between quality of life of children with FASD or PAE and the affect on their families? Are there any additional factors that affect quality of life and family impact, such as family socioeconomic status (SES), child's foster care status, age at assessment, or adverse home environment?

It is hypothesized that children with FASD or PAE will have lower quality of life than typically developing children, particularly in the areas of social, school, emotional, and cognitive functioning, and that children with FASD will be more impaired than the children with PAE only, particularly in the areas of school and cognitive functioning. Additionally, it is hypothesized that FASD and PAE will be associated with a negative impact on the family, especially in the domains of relationships, community, and social life. It is expected that FASD will have a larger negative impact on the family than PAE in several areas because the individuals in the FASD group have a clinical diagnosis, and those in the PAE group do not. Lastly, it is hypothesized that other life and environmental factors may potentially correlate with impaired quality of life and increased caregiver and family impact for those with FASD or PAE.

Significance

The present study is the first to compare the quality of life of children with FASD to children with PAE only, as well as a typically developing control group. Measures of quality of life in FASD research are an important to understand how the disability impacts the daily functioning of affected individuals, both from their own perspectives, and the perspectives of their caregivers. As shown in the literature, individuals with FASD require supports and services across the lifespan and so it is critical to understand which areas are the most impacted, in order to be able to develop supports and services that are targeted where they are most needed. Very little is known about how quality of life is affected in individuals with PAE only, and a better understanding of this group is needed.

Measuring the impact of FASD and PAE on the family is important, because it is understood through qualitative literature and anecdotal evidence that caregivers and families are significantly impacted by FASD. Caregivers need and benefit from resources and supports, and families have shown to respond well to interventions, however more research is needed in this area.

Quantitative research and evidence are needed to inform policy and practice around interventions, supports, services, and resources, and a better understanding is needed around how FASD and PAE impact the family and caregivers in different domains.

Although there are existing studies that examine the impact of FASD on caregivers (Paley et al., 2005; 2006), the present study is the first to look at correlations between quality of life and the impact on the family as well as with other life/environmental factors. This analysis may provide unique and valuable information on how other factors influence the impact of FASD and PAE on the quality of life and the families and caregivers of the affected. The results of this study will provide a profile of functioning and impact across several domains for children with FASD or PAE as well as their families and caregivers.

Methods

Participants

Participants in this study included 39 individuals with FASD, 21 with PAE, and 29 typically developing controls, all ages 6 to 16. See Table 1 for detailed demographic information. The FASD participants all had diagnoses on the FASD spectrum: FAS, *n* = 2 (7.7%); pFAS, *n* = 4 (10.3%); SE/AE, *n* = 19 (48.7%); and ND/AE, *n* = 13 (33.3%). IQs were obtained from clinic files for participants with FASD and PAE; children with FASD had significantly lower FSIQ than those with PAE, which is to be expected given that PAE participants would be expected to be less severely impaired. Groups also differed significantly on mean number of living arrangements but were otherwise similar on all other characteristics.

The participants in this study were recruited as part of a larger study on neurobehavioural outcomes of children with PAE or FASD. All caregivers signed an informed consent form that described the study and explained that the study is voluntary and they could withdraw without consequence. For children in foster care, the legal guardian (e.g., the social worker) signed the consent form. Children and adolescents who were assessed for FASD at the Glenrose Rehabilitation Hospital (GRH) FASD clinic between 2001 and 2010 were contacted by staff from the GRH FASD clinic and/or researchers, to ask if they would like to participate in the proposed study looking at outcomes in this population. Typically developing control participants were recruited from local schools.

The GRH FASD clinic uses the Canadian Guidelines for Diagnosis (Chudley et al., 2005), along with the 4-digit diagnostic code (Astley, 2004), which ranks four diagnostic criteria (prenatal alcohol exposure, CNS dysfunction, growth deficiency, and facial anomalies) on a 4-point Likert scale, with higher scores being worse. Prenatal factors such as genetics and exposure to other teratogens, and postnatal factors including abuse and/or neglect, and comorbid diagnoses, are also measured and considered during assessment. To be assessed at the GRH FASD clinic, a child must score a three or four in the alcohol category of the 4-digit diagnostic code, which is indicative of confirmed prenatal alcohol exposure. A ranking of four indicates an exposure pattern that places the fetus at “high risk,” meaning at least weekly mean high blood alcohol concentrations in early pregnancy (Astley, 2004), and a raking of three indicates confirmed alcohol exposure, but at a level of maternal alcohol use that is less than a rank four, or an unknown level. Confirmation and amounts of alcohol exposure, when available, are obtained from parental interviews, birth documents, health records, and an extensive review of prenatal history, and are validated by the GRH FASD clinic’s social worker. A child must also receive a minimum score of two in the brain category to receive a diagnosis on the FASD spectrum, which means they must have two or more deficits in: academic achievement, attention, cognition, brain-structure, memory, hard and soft neurological signs, executive functioning, or adaptive functioning. Children who do not score high enough in the growth, facial, and/or brain categories to receive an FASD diagnosis are still considered PAE due to receiving a three or four in the alcohol category.

The GRH FASD diagnostic team is multidisciplinary, and includes a developmental pediatrician, a psychologist, a social worker, a speech-language pathologist, and an occupational therapist. Rating scales, interviews, clinical observations, photographic analysis, formal standardized and non-standardized measures, as well as information from multiple sources including families, caregivers, schools, community clinicians and Alberta Child and Family Services, are all used in assessment.

The GRH FASD clinic is one of the largest diagnostic FASD centres in the country, and clinic documentation reports that the geographic distribution of its patients is comparable to other FASD clinic populations in Canada. Therefore, the results of this study are generalizable to children with FASD or PAE and their caregivers, across Canada. Naturally, not all caregivers of children with FASD or PAE access diagnostic clinics, so un-assessed individuals who were prenatally exposed to alcohol are not represented by these results.

Measures

Pediatric Quality of Life Inventory 4.0 (PedsQL). The PedsQL (© 1998-2012 James W. Varni, Ph.D. All rights reserved.) is 23-item survey that measures quality of life in two parallel forms: a child self-rating and a caregiver proxy-report form (Varni, Seid, Knight, Uzark & Szer, 2002). The PedsQL consists of 23 questions in four categories: Physical, Emotional, Social, and School Functioning. There are three parallel surveys for different age categories: Young Child (ages 5-7), Child (ages 8-12), and Teen (ages 13-18). The survey takes approximately 10 minutes, and asks respondents to rate how much each item has been a problem in the past month. Each question is rated on a 5-point Likert scale (0 = never; 1 = almost never; 2 = sometimes; 3 = often; 4 = almost always), with the exception of the self-report Young Child survey, which is simplified into a 3-point Likert scale (0 = never; 2 = sometimes; 4 = almost always). The self-report Young Child survey is further simplified, by showing different faces to correspond to the ratings (smiling face = never; neutral face = sometimes; frowning face = almost always) (Varni, Seid, & Kurtin, 2001). Items are reverse-scored on a scale of 0 to 100 (0 = 100; 1 = 75; 2 = 50; 3 = 25; 4 = 0), with higher overall scores indicating better quality of life. The total scores for each category are calculated by summing the scores of each question and dividing by the number of questions in the category (Varni et al., 2001).

The Physical Functioning scale consists of items asking about physical abilities, including difficulty walking more than one block or running, bathing or showering independently, and doing sports or exercise, as well as whether or not the individual experiences pain or low energy. The Emotional Functioning scale asks how often the individual experiences fear, sadness, anger, or worry, and whether or not they have trouble sleeping. The Social Functioning scale inquires about difficulty getting along with peers, experiencing teasing or exclusion, and difficulty keeping up with or doing the same activities as peers. The School Functioning domain asks whether the individual misses school due to appointments or not feeling well, and whether they have difficulty paying attention in class, remembering things, or keeping up with schoolwork. In addition to the four core scales, the PedsQL has several disease and condition specific models; the Cognitive Functioning scale was added to this study to capture the impact of FASD and PAE on quality of life. The Cognitive Functioning scale consists of six additional items measured and scored in the same manner as the four core scales, which inquire about difficulties with attention and memory, thinking quickly, and remembering more than one item at a time.

For group comparisons on the PedsQL, the internal consistency reliability Cronbach scores generally exceed standards of 0.70, and the Total Scale score across the ages for both self-report and caregiver proxy-report approach an alpha of 0.90 (Varni et al., 2001). Construct validity of the PedsQL has been demonstrated in several populations by its ability to accurately differentiate health-related quality of life between typically developing children and children with chronic or acute health conditions (Varni et al., 2001). Scoring of the PedsQL questionnaires is non-subjective, as it is not a test and there are no correct or incorrect answers. The questionnaires were filled out personally by the participants in this study, eliminating the possibility of researcher bias or measurement inconsistency.

The Generic Lifestyle Assessment Questionnaire (LAQ-G). The Generic Lifestyle Assessment Questionnaire (LAQ-G) is a validated tool developed to measure the impact of childhood disability on the child and the family (Jessen, Colver, Mackie, & Jarvis, 2003). The LAQ-G is a survey that consists of 46 items contained in 35 questions to be completed by the caregiver, and takes approximately 20 minutes to complete. Impact of the child's disability is measured across six health domains: Communication, Mobility, Self-care, Domestic life, Interpersonal Interaction and Relationships, and Community and Social life. Items are scored on a three, four, or five-point Likert scale, with zero always denoting 'no problem' (Jessen et al., 2003). Items in each category are scored and summed to produce a raw score that is converted to a domain score by multiplying it by a constant. Domain scores on the LAQ-G range from 0 to 100, with higher scores indicating more impact of the disability on the family (Jessen et al., 2003). Scoring of the LAQ-G questionnaire is non-subjective, as it is not a test and there are no correct or incorrect answers. The questionnaires were filled out personally by the participants in this study, eliminating the possibility of researcher bias or measurement inconsistency.

The LAQ-G was originally developed as a tool to measure the impact of childhood cerebral palsey (Mackie, Jessen, & Jarvis, 1998), and was adapted to capture the impact of any childhood disability on the family (Jessen et al., 2003). The new version of the LAQ-G was piloted on 95 caregivers of children with disabilities (cases), and 69 caregivers of typically developing children (controls). The pilot study results showed significant discriminative validity ($p < .05$), and high test-re-test reliability and interreporter reliability (Jessen et al., 2003). A multidimensional scaling (MDS) method was used on the data from the 95 case children and items were grouped based on their conceptual relationships and according to their clustering within a two-dimensional solution.

The Communication domain asks how the child communicates (verbally, non-verbally, or both) and whether they communicate easily and often, only with familiar people, or only to convey wants or needs. The Mobility domain inquires about the child’s physical abilities, adaptations to the home, and how much physical assistance the child requires. The Self-Care domain asks how much help the child needs with every day tasks, such as washing hands or getting dressed. The Domestic Life category is a broad domain that includes questions about how many times the child required some treatment, medicine, or therapy at home, how many days of school the child missed in the past month, whether or not cost of looking after the child has created financial difficulties for the family, and amount of contact and/or home visits with professionals regarding the child. The domain of Interpersonal Interactions and Relationships includes items about the child's interactions with others, any behavioural issues such as noise or tantrums, stress experienced by other children in the home, child outings, and participation in extracurricular activities. The last domain, Community and Social Life, is also quite broad, asking about the child getting along with siblings and peers, playing games or with toys, time spent occupying self, difficulty organizing family outings or holidays, impact on caregiver employment, impact on caregiver in the areas of stress and social life, travel to and from school, suitability of child's school, difficulty getting care for or a break from the child, and whether or not society and the community are supportive and understanding of the child. While there are several measures available to measure quality of life in children with disabilities and their caregivers, the LAQ-G is the first tool designed to capture the impact of childhood disability on the family, which is an object health construct (Jessen et al., 2003).

Demographic and health questionnaire. Extensive demographic and health information were also collected from caregivers in a questionnaire format. Questions relevant to this study included: SES, foster care status, the number of foster placement and living situations of the child, whether the child has experienced abuse and/or neglect, or has lived in a poor quality home or adverse home environment. For the control group, participants were excluded if there was any report of prenatal alcohol exposure on the demographic questionnaire. SES was measured using the Hollingshead's Four-Factor Index of Social Status.

Techniques and Study Design

For the FASD and PAE groups, participating children and caregivers completed the PedsQLs, LAQ-G, and demographic and health questionnaire at a testing space in the GRH. The control group was contacted by phone and completed the questionnaires by mail; stamped, self-addressed envelopes were provided for return of the questionnaires. A research assistant was available in person or by telephone to assist all of the participants with the forms if needed. The PedsQL and LAQ-G questionnaires were scored and entered into SPSS for analysis by a research assistant, along with the demographic and health information.

Statistical Analyses

Statistical analyses were completed using SPSS Version 17. Descriptive statistics, including means and standard deviations, were calculated for the three types of questionnaires. For the Child and Caregiver PedsQLs I did separate 3 (group: FASD, PAE, control) by 5 (PedsQL subscales) multivariate analyses of variance (MANOVAs) with repeated measures on the last variables, looking at the self- and caregiver-rated child outcomes. Both MANOVAs were to determine if performance differed across group, whether there was a profile across the domains, and if there was an interaction. Tukey's HSD was included to determine which of the three groups differed on the significant ANOVAs. I also ran separate one-way ANOVAS comparing the child and caregiver reports, to determine internal validity.

To determine external validity, ratings for the control group on each of the Child and Caregiver PedsQL domains were compared to normative data (taken from a separate study utilizing the PedsQL), using one-sample t-tests. One-sample t-tests were also performed to determine if the PAE and FASD groups differed from acutely ill and chronically ill children (taken from a separate study). Additionally, I compared the caregiver ratings and child self-ratings on the PedsQL domains using paired-samples t-tests, to determine if there were overall differences between how the caregivers rated the children and how the children rated themselves.

For the LAQ-G I did a 3 (group: FASD, PAE, controls) by 6 (LAQ-G subscales) MANOVA with repeated measures on the last variable. This analysis was to determine if performance differed across group, whether there was a profile across the domains, and if there was an interaction. Tukey's HSD was included to determine which of the three groups differed on the significant ANOVAs.

Finally, I conducted separate Pearson Correlations for each of the three groups, between scores on the Child and Caregiver PedsQLs, the LAQ-G, and several additional demographic and life/environmental variables, to determine if there were correlations between quality of life scores, family stress ratings, and other factors such as age at assessment, experience of abuse, foster care status, and SES.

Results

MANOVAS and Post Hoc Tests

The three groups (FASD, PAE, controls) were compared on the five domains of the PedsQL (Child and Caregiver proxy reports), and the six domains of the LAQ-G, using separate MANOVAs, to determine if there were between-group differences.

Child PedsQL results. The overall MANOVA for the Child PedsQL was significant $F(10, 164) = 1.99$, $p = .037$, $\eta^2 = .108$. There were significant group differences on three of the five domains: Emotional Functioning[a], $F(2, 85) = 3.34$, $p = .040$, $\eta^2 = .073$, School Functioning, $F(2, 85) = 9.72$, $p < .001$, $\eta^2 = .186$, and Cognitive Functioning, $F(2,85) = 5.80$, $p = .004$, $\eta^2 = .120$. The Social domain approached significance, $F(2,85) = 2.65$, $p =.076$, $\eta^2 = .059$, and the Physical domain was not significant, $F(2,85) = 2.39$, $p = .098$, $\eta^2 = .053$. Tukey's HSD was

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[a] For this variable, the homogeneity of variance assumption is violated, however the Brown-Forsythe test was run and results were similar to the ANOVA.

performed to determine which groups differed significantly. See Table 2 for means and Tukey's HSD results.

Caregiver PedsQL results. The overall MANOVA for the Caregiver PedsQL was significant $F(10, 158) = 5.04$, $p < .001$, $\eta^2 = .242$. There were significant group differences on all five domains: Physical Functioning[b], $F(2,82) = 4.05$, $p = .021$, $\eta^2 = .090$, Emotional Functioning, $F(2,82) = 11.47$, $p < .001$, $\eta^2 = .219$, Social Functioning, $F(2,82) = 18.30$, $p < .001$, $\eta^2 = .309$, School Functioning, $F(2,82) = 18.22$, $p < .001$, $\eta^2 = .308$, and Cognitive Functioning, $F(2,82) = 26.35$, $p < .001$, $\eta^2 = .391$. See Table 3 for means and Tukey's HSD results.

LAQ-G results. The overall MANOVA for the LAQ-G was significant $F(12, 152) = 5.24$, $p < .001$, $\eta^2 = .293$. There were significant group differences on three of the six domains: Domestic Life[c], $F(2, 80) = 4.30$, $p = .017$, $\eta^2 = .097$, Interpersonal Interactions and Relationships, $F(2, 80) = 9.12$, $p < .001$, $\eta^2 = .186$, and Community and Social Life[d], $F(2, 80) = 27.84$, $p < .001$, $\eta^2 = .410$. Three of the six domains were not significant: Communication, $F(2, 80) = 0.21$, $p = .808$, $\eta^2 = .005$, Self Care, $F(2, 80) = 0.18$, $p = .833$, $\eta^2 = .005$, and Mobility, $F(2, 80) = 2.47$, $p = .091$, $\eta^2 = .058$. See Table 4 for means and t-test results.

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[b] See Footnote a.

[c] See Footnote a.

[d] See Footnote a.

Caregiver vs. Child Self-Rating on the PedsQL

Paired-samples t-tests were performed to determine whether there were differences between caregiver ratings and child self-ratings on the five PedsQL domains. A Bonferroni correction was used (.05/5 comparisons) to determine an α of .01. For the PAE and control groups, no significant differences were found between caregiver and child ratings (all *p*s > .01). For the FASD group, however, there were significant differences between caregiver and child ratings on three of the five domains, with caregivers ratings being significantly lower than child self-rating in the areas of Social Functioning, $t(34) = 4.35$, $p < .001$, School Functioning, $t(34) = 2.76$, $p < .001$, and Cognitive Functioning, $t(34) = 4.17$, $p < .001$.

External Validity.

One-sample t-test were used to determine external validity of the control group by comparing their scores to mean scores of a typically developing control children in a study by Varni et al. (2001), which had *n*s averaging 396 for child self-reports and 690 for caregiver reports. Scores were compared on four of the five domains: Physical, Emotional, Social, and School Functioning (the Varni et al. study did not include the Cognitive Functioning domain). A Bonferroni correction was used (.05/4 comparisons) to determine an **α** of .013. For child self-ratings, there were no significant differences found on any of the four domains (all *p*s > .013). For caregiver ratings, none of the domains were significant (all *p*s > .013), however the School Functioning domain approached significance: *t*(28) = -2.35, *p* = .026. The mean School Functioning score for the control group in this study (78.89) is lower than the mean score of the typically developing children in the Varni et al. (2001) study (85.47), indicating that the sample of typically developing control children in this study had lower overall caregiver ratings of School Functioning compared to a larger population of American children.

FASD and PAE vs. Chronically and Acutely Ill Children

The study by Varni et al. (2001) included two other groups of children: chronically ill and acutely ill. Chronically ill children were reported by their parents as having the presence of a chronic health condition, and acutely ill children were not reported as having a chronic health condition, but were recruited from four specialty clinics: orthopedics, cardiology, rheumatology, or diabetes. One-sample t-tests were performed to compare the FASD and PAE groups from the present study to the chronically and acutely ill groups in the Varni et al. (2001) study. For comparisons of both the child self-ratings and the caregiver ratings, an **α** of .00625 was set using a Bonferroni correction (.05/8 comparisons being done per group). Table 5 shows the results of the child self-ratings. The FASD group and chronically ill group only differed significantly on one domain, with the FASD group self-rating as having poorer quality of life in the area of Emotional Functioning, compared to the chronically ill group of children. The FASD group also had significantly lower Emotional Functioning scores compared to the acutely ill group, as well as having significantly lower ratings on the Social and School Functioning domains. The PAE group only differed from the chronically ill and acutely ill populations from the Varni et al. (2001) study on one domain, with the PAE group self-rating as having significantly poorer quality of life in the area of School Functioning than both groups.

Table 6 shows the results of the t-tests between the Varni et al. (2001) samples and the caregiver PedsQL ratings for the FASD and PAE groups in the present study. The FASD group was rated as having significantly poorer quality of life in the areas of Emotional, Social, and School Functioning compared to both the chronically ill and acutely ill groups. The PAE group was rated by caregivers as having poorer quality of life than the chronically ill and acutely ill children in the areas of Social and School Functioning, as well as Emotional Functioning, but only compared to the acutely ill population.

Correlations

Pearson correlations were done between the LAQ-G, Child PedsQL, Caregiver PedsQL and additional variables. Correlations were done separately by group (FASD, PAE, controls) with an **α** of .01. Correlation results are presented in Tables 7-9. On the PedsQL, lower scores indicate poorer functioning in a domain, whereas on the LAQ-G, higher scores indicate higher levels of negative impact.

FASD correlations. See Table 7 for correlations between the LAQ-G and the Child and Caregiver PedsQLs for the FASD group. Correlations were examined between the Child and Caregiver PedsQLs, and the only significant correlation was between the Social Functioning domains, *r*(33) = .46, *p* = .006. As shown in Table 7, there were significant correlations between the Physical Functioning domain of the Child PedsQL and the Mobility, Self-Care, and Interpersonal Interactions & Relationships domains of the LAQ-G for the FASD group. There were also several negative correlations between the LAQ-G and Caregiver ratings on the PedsQL: Social Functioning was correlated with Interpersonal Interactions and Relationships, as well as Community and Social Life. Caregiver rated Emotional Functioning was correlated with Domestic Life, and approached significance with Community & Social Life. A correlation between Mobility (LAQ-G) and Physical Functioning (Caregiver PedsQL) also approached significance.

I also examined correlations between demographic variables (IQ, SES, age, age at assessment), life/environmental factors (child ever being in foster care, number of different living situations and foster care placements, ever living in a poor quality home, ever experiencing abusing/neglect, being exposed to an adverse home environment) and the three measures in this study (Child and Caregiver PedsQLs, LAQ-G). There were correlations found between the child's age and two LAQ-G domains: Self Care, *r*(37) = -.43, *p* = .007, and Interpersonal Interactions and Relationships, *r*(37) = -.47, *p* = .002. A significant correlation was also found between child’s age and self-rated Physical Functioning on the PedsQL, *r*(36) = .47, *p* = .003. Experience of abuse and/or neglect was correlated with Emotional Functioning *r*(34) = .43, *p* = .009, and Cognitive Functioning, *r*(34) = .43, *p* = .009, on the Child PedsQL, as well as the number of different living situations of the child, *r*(35) = .66, *p* < .001, and having lived in a poor quality home, *r*(35) = .76, *p* < .001. Living in a poor quality home was also correlated with the number of different living situations, *r*(35) = .62, *p* <.001. There were no correlations found between the three measures (Child PedsQL, Caregiver PedsQL, LAQ-G) and eight of the 10 demographic and life/environmental factors: IQ, age at assessment, SES, number of foster care placements, number of living situations, ever being in foster care, having lived in an adverse home environment, or having lived in a poor quality home.

PAE correlations. For the PAE group, there were no significant correlations between the LAQ-G and the Child PedsQL. There was only one significant correlation between the Child and Caregiver PedsQLs: self-rated Physical Functioning on the Child PedsQL was significantly correlated with caregiver ratings of Cognitive Functioning, *r*(19) = .63, *p* = .002. There were several significant correlations between the LAQ-G and the Caregiver PedsQL, as shown in Table 8. The Community and Social Life domain of the LAQ-G was significantly correlated with the Physical and School functioning domains of the Caregiver PedsQL, and approached significance with the Cognitive Functioning domain. The Communication domain of the LAQ-G and caregiver ratings of

Cognitive Functioning were also correlated, and the Domestic Life domain of the LAQ-G and the Emotional Functioning domain of the Caregiver PedsQL approached significance.

For PAE group I also examined correlations between the three measures in this study and the demographic and life/environmental variables. Child IQ was significantly correlated with the number of foster placements they had had to date *r*(12) = .77, *p* = .001. Ever experiencing abuse and/or neglect was significantly correlated with several factors, including: the number different living situations of the child, *r*(18) = .58, *p* = .007, having lived in a poor quality home, *r*(18) = .73, *p* < .001, having lived in an adverse home environment, *r*(18) = .81, *p* < .001, as well as the Emotional Functioning domain of the Caregiver PedsQL, *r*(18) = -.67, *p* = .001. The age at which the child was assessed at the FASD clinic was correlated with two of the LAQ-G domains: Domestic Life, *r*(18) = -.64, *p* = .002, and Interpersonal Interactions and Relationships, *r*(18) = -.58, *p* = .007. There were no significant correlations between IQ, age, SES, number of living situations, ever being in foster care, number of foster care placements, having lived in an adverse home environment, or having lived in a poor quality home and any of the three measures.

Control correlations. The only significant correlation for the control group between the Child and Caregiver PedsQLs was between both Social domains, *r*(26) = .57, *p* = .002. There were many significant correlations between the LAQ-G and Caregiver PedsQL domains (see Table 9). The LAQ-G and the Child PedsQL did not correlate on any domains, although Community and Social Life (LAQ-G) and the Social Functioning domain (Child PedsQL) approached significance, $r(27) = -.45$, $p = .015$. There were no correlations for the control group between any of the demographic or life/environmental variables (age, SES, number of different living situations or foster care placements, ever being in foster care, or living in an adverse home environment) and any of the 3 measures. The other additional life variables analyzed for the FASD and PAE groups were not available for the control group (IQ, age at assessment, experience of abuse and/or neglect, or living in a poor quality home.).

Impact of Living Situation

Finally, I wanted to determine if different family living situations impacted quality of life or the impact of FASD and PAE on the family. For this analysis, the FASD and PAE groups were combined, as there were small sample sizes in each living situation group, and the previous analyses demonstrated that there were very little differences between the alcohol exposed groups in quality of life or the impact on the family. The participants were divided into three groups: Kinship/Bio families ($n = 18$), Adoptive families ($n = 26$), and Foster families ($n = 16$). The overall MANOVA was not significant for any of the three surveys: the Child PedsQL, $F(10, 106) = 0.79$, $p = .640$, $\eta^2 = .069$, the Caregiver PedsQL, $F(10, 102) = 1.60$, $p = .117$, $\eta^2 = .136$, or the LAQ-G, $F(12, 94) = 1.24$, $p = .265$, $\eta^2 = .137$.

Discussion

The goals of this study were to compare the quality of life of children with FASD, PAE, and typically developing controls, as well as the impact of FASD and PAE on families and caregivers. Measures were compared across the different domains, as well as with additional demographic and life/environmental factors, including: IQ, age, age at assessment, SES, number of different living situations, foster care placements, having experienced abuse and/or neglect, or having lived in a poor quality home or adverse home environment.

This is the first study to look at the quality of life of children diagnosed with an FASD compared to children who were prenatally exposed but not qualifying for a diagnosis. One previous study examined the quality of life of children with FASD (Stade et al., 2005), however results were compared to normative scores rather than a locally recruited, typically developing control group, and did not include a prenatally exposed but not diagnosed group. The present study is the first to look at the impact of FASD and PAE on the family using the LAQ-G, and also the first to combine analyses of quality of life, family impact, and demographic and life/environmental factors.

Quality of Life

Child self-rated quality of life. The PAE and FASD groups self-rated as having significantly poorer quality of life than controls in the areas of School and Cognitive Functioning. Prenatal alcohol exposure may lead to brain injuries, including impairments in executive functioning, processing speed, visual-spatial abilities, academic achievement, attention, learning, and memory (Kodituwakku, 2007; Mattson et al., 2011; Riley at al., 2011; Riley & McGee, 2005), and thus it is not surprising to see that both of the alcohol-exposed groups were significantly impaired in the areas of quality of life related to cognition and school.

The FASD and PAE groups did not rate their quality of life as being more impaired than controls on the Physical Functioning domain; although prenatal alcohol exposure is associated with some physical impairment (e.g. CNS damage etc.), it is not typically viewed as a physical disability. PAE and FASD self-ratings of Social Functioning were also not rated significantly different than that of controls, which is unexpected because it is noted repeatedly in the literature that individuals with PAE or FASD have impairments in social skills and social functioning (see Kully-Martens, Denys, Treit, Tamana, & Rasmussen, 2012, for review). The absence of a significant difference in this domain could possibly be related to individuals with PAE or FASD not being aware of their social impairments or difficulties. For example, the PedsQL Social domain includes questions such as “I have trouble getting along with other teens” and “It is hard to keep up with my peers.” Individuals with social skills deficits may not be able to recognize that they are in fact having difficulties keeping up or getting along with their peers. The FASD group self-rated significantly lower than controls on Emotional Functioning, which confirms previous research showing poor emotional functioning in children with FASD (Pei et al., 2011). It is interesting to note that the PAE group did not rate themselves as significantly lower than controls in this area, although the PAE and FASD groups did not differ significantly from each other on this domain.

Caregiver-rated quality of life. Both the FASD and PAE groups were rated significantly lower than controls on all domains of the caregiver PedsQL (except for PAE vs. controls on Physical Functioning, which approached significance). It is interesting to note that caregivers rated the PAE and FASD children as having poorer quality of life in the Social and Physical Functioning domains compared to typically developing controls, yet this comparison was not significant in the FASD and PAE self-ratings. One possibility is that caregivers may be better able to report on behaviours such as having difficulty getting along with peers, being teased, or not being able to keep up with peers. Caregivers also rated the children with PAE or FASD as having poorer physical functioning than their typically developing peers, when again, this finding was absent from the child self-ratings. The Physical Functioning domain includes questions about problems with running, bathing/showering independently, doing chores, having hurts or aches, and having low energy levels; it is likely that caregivers of children with PAE or FASD are able to identify physical impairments more objectively through observation of other children (e.g. other children in the home or neighbourhood) who do not have the same physical limitations.

Child vs. caregiver ratings of quality of life. In comparing Child vs. Caregiver PedsQL ratings, no significant differences were found in the PAE or Control groups, however there were several differences in the FASD group.

Within the FASD group, caregivers rated their children significantly lower than the children rated themselves in the Social Functioning, School Functioning, and Cognitive Functioning domains. As mentioned earlier, children with FASD may be unaware of their own social impairments, thus rating their own social abilities as higher than they would be by an outside observer. Caregivers may also be more aware of impairments in school and cognitive functioning, due to having access to test results, having meetings and conversations with clinic staff, teachers, etc. and also being able to assess their child's impairments objectively. A child who has cognitive deficits may be unable to conceptualize what life would be like, for example cognitively or socially, if they did not have these impairments.

Impact on families and caregivers

Caregivers of children in both the PAE and FASD groups rated the impact on the family as being greater than controls in the area of Community and Social Life. This domain includes questions about both the child's interactions with others, their ability to play or occupy themselves, impact on the family's social outings and the caregiver's own social life, and the school and community's understanding of the child's disability. This finding confirms previous research that prenatal alcohol exposure impacts social skills (Kully-Martens et al., 2012), as well as the needs of caregivers for respite and understanding from the community and others (Brown & Bednar, 2004; Giutna & Stressiguth, 1998).

Caregivers of both children with PAE and FASD rated the impact on the family as being more severe than controls in the area of Interpersonal Interactions and Relationships. This domain is about the interactions and relationships that the child has with the family and caregiver, and asks questions that encompass the burden of demands of the child on the caregiver and the family (e.g. placing extra stress on other children in the home, whether or not the child has outbursts or temper tantrums, how often the child is able to leave the home etc.). Children with FASD or PAE have high levels of externalizing behaviours, and several studies have shown this to be linked to higher levels of caregiver stress (Paley et al., 2005; 2006). It is possible that in the present study, high levels of behaviour problems create stressful interactions between the child and the rest of the family, and increase caregiver burden.

The caregivers of children with FASD rated the impact on the Domestic Life domain significantly greater than the controls. The Domestic Life domain focuses on the how the child's special needs impact the family and the daily functioning of the caregiver in terms of finances, and time. These results support previous findings that children with FASD require specialized supports and services (Jirikowic et al., 2010), and that caregivers and families of children with FASD can also benefit from interventions, services, supports, and resources (Chudley et al., 2005; Leenaars et al., 2012; Olson et al., 2009; Paley et al., 2006; Streissguth, 1997; Streissguth & O'Malley, 2000) to help cope with the increased needs and demands of the child. There was no significant difference found between the PAE group and the control group in this domain, which is surprising because most other findings in the current study have shown a very similar pattern of results between the PAE and FASD groups on all three measures. The Domestic Life domain includes questions about the child's visits with professionals and missing school because of appointments; perhaps the PAE children in this study had less contact with professionals due to not having a diagnosis and perhaps not qualifying for many of the supports and services available to the FASD group.

External Validity

The external validity portion of this study is important because it characterized our sample of typically developing controls as being comparable to a large sample of other typically developing North American children. These findings are valuable because it shows that the control group in this study did not have elevated functioning in any area, which would have contributed to the differences found between the clinical groups and the typically developing group.

FASD and PAE vs. Chronically and Acutely Ill Children

The comparisons between the children with FASD and PAE in the current study and the Chronically Ill and Acutely Ill chilren from the Varni et al. (2001) study are important because they demonstrate that the FASD and PAE groups were either significantly more impaired, or not significantly different on any single domain of the Child or Caregiver PedsQLs, as shown in Tables 5 and 6. Thus, the children with FASD or PAE in this study had comparable or poorer quality of life than children with acute or chronic conditions in orthopedics, cardiology, rheumatology, or diabetes, all which are considered serious and/or debilitating health issues in pediatrics. The findings for the PAE group are especially important given that these individuals do not qualify for a diagnosis on the FASD spectrum and often do not qualify for specialized services or supports, yet they are experiencing quality of life comparable to or lower than North American children with serious acute or chronic illnesses.

Correlations

FASD correlations. All of the correlations between the two PedsQL domains and the LAQ-G domains were negative, indicating relationships between the domains related to impairment (e.g. Lower scores on PedsQL domains are associated with greater impact on LAQ-G domains and vice versa).

Ratings of Physical Functioning on the Child and Caregiver PedsQLs were correlated with the Mobility domain of the LAQ-G (caregiver rating approached significance). The Mobility domain of the LAQ-G measures the child's need for physical assistance or special equipment, as well as help getting out of bed, and thus this correlation demonstrates that quality of life in the area of physical functioning is related to the child's need (or absence of need) for physical assistance as well as their physical abilities. Physical Functioning on the Child PedsQL was also correlated with the Self-Care domain of the LAQ-G; children who are unable to do many self-care tasks independently may have lower physical quality of life than children who have very little to no issues with completing these tasks.

Lower self-ratings on the Physical Domain (Child PedsQL) were also associated with greater impact on families and caregivers in the Interpersonal Interactions and Relationships domain (LAQ-G). Children who are more physically independent and require less help from an adult may feel more independent and autonomous, contributing to higher ratings of physical quality of life. The Interpersonal Interactions and Relationships domain was also correlated with the Social Functioning domain of the Child PedsQL and may indicate that more demanding children have lower social quality of life, perhaps due to their reliance on their caregivers, or due to their outbursts. The Interpersonal Interactions and Relationships domain also asks questions about how often the child sees their friends outside of school, which may be why this domain is correlated with Social Functioning.

One interesting finding was the significant correlation between caregiver-rated Emotional Functioning (PedsQL) and the Domestic Life domain of the LAQ-G. The relationship between these two domains is likely bidirectional; children who have poorer emotional functioning (e.g. feeling afraid, sad, or angry more often, having trouble sleeping, worrying about the future) may be more impaired by FASD, placing higher demands on caregivers and the family, and families and caregivers who are experiencing increased stress may also be impacting the children's Emotional Functioning. Caregiver stress is related to poorer outcomes for children (see Olson et al. 2009 for review), and caregiver stress has been directly linked to child externalizing behaviours (e.g. acting out) (Paley et al., 2005); however, these relationships are likely bidirectional.

Greater impact on the Community and Social Life domain of the LAQ-G was associated with lower caregiver ratings on the PedsQL of the child's Social and Emotional Functioning (Emotional approached significance). The poor social skills of children with FASD (Kully-Martens et al., 2012) may lead to rejection by others, including their peers, as well as other adults or parents in the community. Correlations between these two domains may reflect that impairments in Social Functioning have further reaching impacts than just the child's peer group; it is very likely that the community and even society may be less understanding of a child that has poor social functioning. The Emotional Functioning domain may be correlated with Community and Social Life for many similar reasons; children who have difficulty regulating their emotions or show emotional outbursts may be less accepted by their peers and the community, and may also make it difficult for caregivers to arrange family outings or find respite care.

The negative correlations between the child's age and Interpersonal Interactions and Relationships domain (LAQ-G) indicate that families of older children may be experiencing less impact in this area. It is possible that caregivers of older children in this study have had more time since their child's diagnosis to adjust their expectations of the child and their parenting style (thus reducing the impact and stress on the family), and also connect with supports and resources. Age was also correlated with Self-Care (LAQ-G) and child self-ratings of Physical Functioning (PedsQL), indicating that the older children had better (self-rated) physical quality of life and were better able to perform self-care tasks than younger children with FASD. Perhaps children with FASD become more confident with their physical abilities and skills with age and experience, or perhaps some types of motor impairments in children with FASD are actually related to developmental delays and eventually improve with age (Mattson et al., 2011).

There were positive correlations found between experience of abuse and/or neglect and having lived in a poor quality home, and the number of living situations of the child, which are not unexpected results. The positive correlations between experience of abuse and/or neglect and the Emotional Functioning and Cognitive Functioning domains of the Child PedsQL indicate that these life experiences may have a negative impact on these two areas of quality of life. The impact on Cognitive Functioning is especially interesting because not only are past experiences of abuse and/or neglect impacting the child on an emotional level, but they may also related to the child having difficulty concentrating, remembering, and thinking. There were no correlations found between the outcome measures and any of the other life or environmental factors (child ever being in foster care, number of different living situations and foster care placements, ever living in a poor quality home, experiencing abuse and/or neglect, or being exposed to an adverse home environment).

PAE correlations. For the PAE group, the only significant correlation between child and caregiver ratings of quality of life was between the Physical Functioning domain (Child PedsQL) and the Cognitive Functioning domain (Caregiver PedsQL). This was an unexpected correlation due to the very small amount of overlap between these two areas. However, it is possible that caregivers perceive children with poorer physical functioning as also being more cognitively impaired.

There were several correlations between LAQ-G domains and the Caregiver PedsQL, with all correlations being negative (related to impairment). The Community and Social Life domain was correlated with caregiver-rated quality of life in the areas of Physical, School, and Cognitive Functioning (Cognitive approached significance). For caregivers of children with PAE, it appears that the child’s physical, school, and cognitive functioning may impact the relationships between the community and the caregiver and child. A child with poorer cognitive functioning may be less able to play alone and interact with others, and may be more demanding of their caregiver’s time, impacting the caregiver’s social life. The caregiver may also have difficulty planning family outings if the child has poor physical functioning. The lower school functioning of the child may also require more time from the caregiver in helping the child with schoolwork and advocating for the child at school with teachers and school staff. Because the participants in the PAE group do not have a formal diagnosis on the FASD spectrum, these children may not receive much needed support in school. For example, Alberta Education provides schools with funding and programming support for children with special needs, however current eligibility for children prenatally exposed to alcohol hinges on having a clinical diagnosis of FASD as well as functional impairments (Alberta Government, 2012).

The Communication domain of the LAQ-G was significantly correlated with the Cognitive Functioning domain of the caregiver PedsQL; there is an obvious correlation between a child's cognitive abilities and their ability to communicate with others, however it is interesting to note that there were no correlations in these areas for the FASD group. The correlation between Domestic Life on the LAQ-G and caregiver-rated Emotional Functioning on the PedsQL approached significance, indicating that the relationship between the child's emotional functioning and the demands placed on the family and caregiver are likely bidirectional. Interestingly, there were no correlations between the Child PedsQL and the LAQ-G for the PAE group, whereas for the FASD group there were significant correlations only with the Physical Functioning domain of the Child PedsQL. Both the PAE and FASD groups may lack self-awareness or have memory impairments that make it difficult to rate their functioning in other domains accurately.

For the PAE group, there were several correlations found when looking at additional life factors. Higher IQ was highly correlated with having lived in more foster placements, however this association must be viewed with caution due to having low *n*s of IQs in the PAE group. It is possible that children with PAE who have higher IQs are more difficult to care for, as they may still have cognitive and behavioural deficits, but may still be higher functioning and get into trouble more easily. Another possibility is that because these children do not have a formal diagnosis, some foster parents may have difficulty understanding their impairments, and be less understanding and more impatient with their behaviours, especially if the children have IQs in the normal-average range. All of these factors may contribute to placement breakdown, increasing the number of foster care placements the child will experience.

Not surprisingly, the number of living situations and living in an adverse home environment were both positively correlated with experiencing abuse and/or neglect. There was a negative correlation between experience of abuse and/or neglect and caregiver-rated Emotional Functioning on the PedsQL, indicating that experience of abuse and/or neglect may affect Emotional Functioning. Olson and colleagues (2006) describe the negative life experiences of children with FASD as a type of “double jeopardy” because in addition to the impacts of being prenatally exposed to alcohol, many of these children also live or have lived in poor caregiving environments and may experience things such as abuse, neglect, and/or poverty.

Control correlations. The only correlation between the Child and Caregiver PedsQLs in the control group was between the Social Functioning domains, which was also the case for the FASD group. It appears that for children of all ranges of functioning, there is a lack of agreement between what caregivers observe and how the children observe themselves. There were many correlations found between LAQ-G domains (Mobility, Self-Care, Interpersonal Interactions and Relationships, and Community and Social Life) and caregiver-rated quality of life (including Physical, Emotional, Social, and Cognitive Functioning).

Impact of Living Situation

An additional analysis was done to examine the influence of different family living situations on quality of life and family impact. Although some researchers suggest that family type is important and that different types of families respond to and care for children with FASD differently (Olson et al., 2006), family type did not appear to have any influence in this study. Much of the FASD literature on family types has focused on the differences between biological and adoptive/foster families, however in this study, very few of the PAE and FASD participants lived with a biological caregiver (4.8 and 15.4% respectively), making analyses difficult. It is interesting to note, however, that there were not differences even between the adoptive and foster families.

Comparisons between Children with PAE and FASD

There were no differences between the PAE and FASD groups on any of the domains of the LAQ-G or the caregiver and child PedsQLs, which is noteworthy because the individuals in this study with FASD have a formal clinical diagnosis, and those in the PAE group do not. These two alcohol-exposed groups did not differ from each other on any of the Child or Caregiver PedsQL domains, indicating that they are both experiencing the same impacts on their quality of life. This finding is significant, because as stated earlier, individuals with PAE do not qualify for some much-needed supports and services, including funding and programming in schools, yet as these results show, their quality of life is impacted by their disability.

One interesting finding was that although the two groups did not differ in caregiver or self-rated School Functioning, caregiver-rated School Functioning was significantly correlated with the Community and Social Life domain of the LAQ-G in the PAE group (but not the FASD group). The Community and Social Life domain includes questions about whether or not the caregiver feels that society and the community are supportive and understanding of their child. The child's difficulties at school without the much needed supports and services may be leading caregivers of children with PAE to feel unsupported and like their child is misunderstood.

My initial hypothesis was that FASD would have a greater impact on the family than PAE, however the results of this study show that the PAE and FASD groups did not differ significantly from each other on any of the LAQ-G domains. These results further bolster the findings related to quality of life and show that despite one group not qualifying for a diagnosis, the FASD and PAE groups are very similar in how they impact the individual as well as the family.

For both the FASD and PAE groups there was a correlation between Domestic Life on the LAQ-G and caregiver-rated Emotional Functioning on the PedsQL (PAE approached significance). As speculated earlier, the relationship between the child's emotional functioning and the demands placed on the family and caregiver are likely bidirectional. Even though PAE children are generally considered less impaired than children with a diagnosis on the FASD spectrum, it appears that they have similar impacts on the family and caregiver in this domain.

The correlations with the demographic and life/environmental factors revealed a similar patterns of results for both the FASD and PAE groups in some areas; for both groups, experiencing abuse and/or neglect was positively correlated with the number of living situations, living in a poor quality home, and Emotional Functioning (Child PedsQ). It appears that these two groups are impacted in very similar ways by their experiences of adverse life outcomes.

Limitations and Future Directions

This study is not without its limitations. The sample sizes in this study are relatively modest, and sample sizes also differ between groups (FASD, PAE, controls). The typically developing controls in this study were not specifically age or gender matched to the exposed individuals, however there were no significant differences between groups in age, gender, or SES. The groups in this study included wide age ranges (6-18 years), and so comparisons by age group were not possible due to having small sample sizes. Future studies with larger sample sizes would allow for better analysis of quality of life between different age groups.

The groups were also not matched on the number of living arrangements they had been in or their current living situation. Children who are prenatally exposed to alcohol are often subject to multiple foster home placements and different living situations, more so than would be expected for a typically developing control group. Thus, matching for type of number of living situations is a frequent limitation in FASD and PAE research.

The correlations found between demographic variables, life/environmental variables, and the quality of life and family impact measures indicate that adverse life situations and experiences may impact quality of life and the family. It is well known that children who are prenatally exposed to alcohol experience “double jeopardy” (Olson et al., 2009), due to experiencing high rates of environmental risk factors, and thus alcohol exposure may not be the only cause of impairment in this study. In population research it is often difficult to tease out the specific impact of one factor (e.g. prenatal alcohol exposure) from other life experiences; thus it is important to view the FASD and PAE populations holistically as a group that is impacted not only by prenatal alcohol exposure, but likely by adverse life and environmental factors as well.

Although patient self-report is considered the standard for measuring quality of life (Varni & Burwinkle, 2006), the comprehension levels of the FASD and PAE participants in this study may have impacted their responses. Individuals were given the questionnaires that matched their chronological ages, and not necessarily their comprehension levels. Research assistants were available to assist the participants and answer questions to help minimize this limitation, however the possibility still exists that the results of the surveys are biased due to issues with comprehension.

One interesting finding in this study was that there were differences between caregiver and child reports of quality of life on the PedsQL. Future studies may want to include a qualitative component or follow-up questions for children and caregivers, to help understand why there are significant differences between how the children and the caregivers are rating the child's quality of life. Additionally, although the PedsQL and LAQ-G are reliable and valid measures, future studies may want to incorporate additional measures of quality of life and family impact.

This study was conducted with children and caregivers who were assessed for FASD at the Glenrose Rehabilitation Hospital's FASD Clinic, one of the largest diagnostic FASD centres in Canada. Our sample is believed to be representative of the overall FASD clinic population seen in this area and in Canada, however the results may not necessarily be generalizable to other parts of the world. It is possible that the groups in this study may be higher functioning, with the FASD group having a mean IQ of 81.79 and the PAE group having a mean IQ of 92.36. Previous studies have estimated an average IQ of 70 for individuals with FAS and 80 for those who are nondysmorphic (see Mattson et al., 2011 for review).

Additionally, the individuals with FASD or PAE and their caregivers who participated in this study were all clinic-referred, and thus may not represent all individuals with prenatal alcohol exposure who have not been assessed at an FASD clinic. This is a significant limitation of any FASD research, as it is impossible to include unidentified individuals who have prenatal alcohol exposure (e.g. those living in remote areas, or individuals whose caregivers are unwilling to have them assessed or unaware of their child having FASD).

The current study is cross-sectional, and a longitudinal study would allow for a better understanding of changes in quality of life and family impact over time. Future research could also benefit from looking at resources that FASD and PAE affected children and their families access, and if this correlates with improvements in quality of life or reduction of impact on the family.

Conclusion

The results of this study have significant implications for the health and outcomes of children with FASD or PAE in Canada. It is imperative to understand how FASD and PAE affect the quality of life of children, and how raising a child with FASD or PAE impact families and caregivers in order to inform the development of appropriate services, supports, and interventions aimed at improving the lives of children and caregivers. Presently there are very few studies on quality of life in FASD, and this is the first study to date to compare quality of life and family impact.

Individuals who were prenatally exposed to alcohol but do not qualify for a diagnosis on the FASD spectrum are considered to be less impaired than those who are diagnosed with an FASD; however, in this study, these two groups had very similar profiles of deficits in quality of life and impact on the family and did not differ significantly from each other on any of the quality of life or family impact domains. Based on these results, it is important to consider expanding funding and criteria for FASD interventions, supports, and services to be provided on a needs basis rather than based on diagnosis.

Much of the previous research and findings on quality of life and family impact in FASD and PAE have been based on qualitative or anecdotal evidence, and thus the findings from this quantitative study are extremely important, especially in advising and informing policies that will support these individuals as well as their families, throughout the lifespan, in order to help ameliorate the impacts of prenatal alcohol exposure.

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Table 1

Participant Characteristics

Demographic Variable	FASD	PAE	Controls	*p*
N	39	21	29	
Age [M (range)]	12.31 (7-18)	11.05 (7-15)	11.27 (6-18)	*.219*[a]
Sex [N female (%)]	22 (56.4)	9 (42.9)	16 (55.2)	*.585*[b]
Full Scale IQ [M (SD)]	81.79 (10.28)	92.36 (7.69)	-	*.001*[a]*
Living situation [N (%)]				*.576*[b]
Biological home	6 (15.4)	1 (4.8)	29 (100)	
Adoptive home	16 (41.0)	10 (47.6)	-	
Foster placement	9 (23.1)	7 (33.3)	-	
Kinship placement	8 (20.5)	3 (14.3)	-	
Number of living situations [M (range)]	3.86 (1-9)	3.33 (1-11)	1.14 (1-3)	*<.001*[a]*
Mean SES [M (SD)]	35.68 (12.84)	33.36 (11.68)	40.64 (9.09)	*.069*[a]

Note: FSIQ Available for 29 FASD participants and 14 PAE participants. SES was obtained from the primary caregiver using the Hollingshead's Four-Factor Index of Social Status.

[a] analyzed by ANOVA, [b] analyzed by chi-square analysis

*p < .001

Table 2

Child PedsQL Means and Tukey's HSD Results

	Mean (SD)			*p* value		
	FASD	PAE	Control	FASD vs. PAE	FASD vs. Controls	PAE vs. Controls
Physical	75.58 (2.69)	76.79 (3.62)	84.16 (3.08)	-	-	-
Emotional	63.42 (3.42)	64.76 (4.60)	76.21 (3.92)	.970	.042*	.147
Social	72.89 (3.48)	69.29 (4.69)	82.41 (3.99)	-	-	-
School	64.47 (2.91)	59.28 (3.91)	75.72 (3.33)	.538	.000*	.002*
Cognitive	61.71 (3.40)	56.94 (4.58)	75.72 (3.90)	.682	.022*	.007*

Note: Missing values (-) were not significant in the overall MANOVA.
*$p < .05$

Table 3

Caregiver PedsQL Means and Tukey's HSD Results

	Mean			*p* value		
	FASD	PAE	Control	FASD vs. PAE	FASD vs. Controls	PAE vs. Controls
Physical	75.87 (3.14)	76.04 (4.11)	88.29 (3.56)	.999	.028*	.068
Emotional	56.39 (3.54)	57.38 (4.63)	80.18 (4.01)	.984	.000*	.001*
Social	55.56 (3.39)	63.57 (4.44)	86.07 (3.84)	.327	.000*	.001*
School	51.81 (2.95)	60.95 (3.86)	78.57 (3.34)	.150	.000*	.003*
Cognitive	39.40 (3.78)	51.98 (4.95)	80.49 (4.28)	.113	.000*	.000*

Note: All domains were significant in the overall MANOVA.
*$p < .05$

Table 4

LAQ-G Means and Tukey's HSD Results

	Mean (SD)			*p* value		
	FASD	PAE	Control	FASD vs. PAE	FASD vs. Controls	PAE vs. Controls
Communication	33.33 (5.97)	31.94 (8.45)	27.59 (6.65)	-	-	-
Mobility	7.63 (1.12)	8.84 (1.58)	4.73 (1.25)	-	-	-
Self Care	6.14 (1.52)	5.10 (2.16)	6.76 (1.70)	-	-	-
Domestic Life	15.75 (2.02)	11.12 (2.86)	6.90 (2.25)	.387	.012*	.481
Interpersonal Interactions & Relationships	45.21 (2.09)	44.17 (2.95)	32.59 (2.32)	.955	.000*	.008*
Community & Social Life	34.93 (2.38)	29.01 (3.37)	8.87 (2.65)	.328	.000*	.000*

Note: Missing values (-) were not significant in the overall MANOVA
**p* < .05

Table 5

FASD and PAE Children (self-ratings) vs. Varni et al. (2001) Children

Domain	FASD	Chronically Ill	*p*	Acutely Ill	*p*
Physical	75.58	77.36	.523	78.88	.240
Emotional	63.42	76.40	.001*	77.33	.000*
Social	72.89	81.60	.016	82.83	.006*
School	64.47	73.43	.009	75.68	.001*
Domain	PAE	Chronically Ill	*p*	Acutely Ill	*p*
Physical	76.79	77.36	.900	78.88	.647
Emotional	64.76	76.40	.017	77.33	.011
Social	69.29	81.60	.044	82.83	.028
School	59.29	73.43	.002*	75.68	.000*

*Significant at $p < .00625$ as determined by Bonferroni correction ($p = .05/8$ t-tests)

Table 6

FASD and PAE Children (caregiver-ratings) vs. Varni et al. (2001) Children

Domain	FASD	Chronically Ill	*p*	Acutely Ill	*p*
Physical	75.87	73.28	.462	81.81	.097
Emotional	56.39	73.05	.000*	78.82	.000*
Social	55.56	79.77	.000*	83.58	.000*
School	51.81	71.08	.000*	74.74	.000*
Domain	PAE	Chronically Ill	*p*	Acutely Ill	*p*
Physical	76.04	73.28	.573	81.81	.246
Emotional	57.38	73.05	.009	78.82	.001*
Social	63.57	79.77	.003*	83.58	.001*
School	60.95	71.08	.044	74.74	.008

*Significant at $p < .00625$ as determined by Bonferroni correction ($p = .05/8$ t-tests)

Table 7

FASD Correlations

		Child PedsQL					Caregiver PedsQ				
		Physical	Emot.	Social	School	Cog.	Physical	Emot.	Social	School	Cog.
LAQ-G	Comm.	-0.223	0.195	-0.183	0.159	0.232	-0.297	-0.266	-0.318	-0.210	-0.225
	Mobility	-0.443**	0.029	-0.249	-0.077	-0.003	-0.424*	-0.193	-0.185	-0.191	-0.157
	Self-Care	-0.501**	-0.247	-0.242	0.057	0.004	-0.255	-0.321	-0.260	-0.237	0.118
	Dom. Life	-0.108	-0.253	-0.109	-0.050	-0.102	-0.066	-0.485**	-0.222	-0.180	-0.085
	Interpers.	-0.516**	-0.184	-0.357	-0.055	-0.038	-0.247	-0.247	-0.454**	0.073	0.072
	Comm. & Soc.	-0.304	-0.249	-0.266	-0.243	0.010	-0.331	-0.421*	-0.526**	-0.35	-0.364

* approached significance, ** *p* < .01

Table 8

PAE Correlations

		Caregiver PedsQL				
		Physical	Emotional	Social	School	Cognitive
LAQ-G	Communication	-0.318	-0.199	-0.337	-0.416	-0.616**
	Mobility	0.124	-0.047	0.302	0.168	-0.251
	Self-Care	-0.394	-0.396	-0.032	-0.344	-0.463
	Domestic Life	-0.353	-0.547*	0.063	-0.241	-0.209
	Interpersonal Interactions & Relationships	-0.388	-0.316	-0.308	-0.236	-0.267
	Community & Social Life	-0.670**	-0.482	-0.458	-0.565**	-0.548*

* approached significance, ** $p < .01$

Table 9

Control Correlations

		Caregiver PedsQ				
		Physical	Emotional	Social	School	Cognitive
LAQ-G	Communication	-0.223	-0.250	-0.135	-0.201	-0.251
	Mobility	-0.520**	-0.448*	-0.358	-0.387	-0.528**
	Self-Care	-0.367	-0.294	-0.443*	-0.0537	-0.215
	Domestic Life	-0.385	-0.353	-0.295	-0.275	-0.261
	Interpersonal Interactions & Relationships	-0.480**	-0.475**	-0.252	-0.134	-0.276
	Community & Social Life	-0.198	-0.520**	-0.550**	-0.166	-0.291

* approached significance, ** *p* < .01