

SLEEP CHARACTERISTICS OF YOUNG ALCOHOL AFFECTED CHILDREN:
A QUANTITATIVE AND QUALITATIVE ANALYSIS

By Ana C. Hanlon-Dearman

A Thesis

submitted to the Faculty of Graduate Studies in partial fulfillment of
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**Sleep Characteristics of Young Alcohol Affected Children:
A Quantitative and Qualitative Analysis**

BY

Ana C. Hanlon-Dearman

**A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University
of Manitoba in partial fulfillment of the requirements of the degree
of**

MASTER OF SCIENCE

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ABSTRACT

SLEEP CHARACTERISTICS OF YOUNG ALCOHOL AFFECTED CHILDREN: A QUANTITATIVE AND QUALITATIVE ANALYSIS

AC Hanlon-Dearman, Departments of Community Health Sciences and Pediatrics and Child Health, University of Manitoba, Winnipeg, Manitoba

BACKGROUND: Fetal alcohol spectrum disorder refers to a group of phenotypic and behavioural anomalies associated with the use of alcohol in pregnancy. The most important of these traits includes growth retardation, characteristic craniofacial anomalies, and central nervous system involvement. Sleep disorders have been identified, but poorly described, in fetal alcohol spectrum disorder.

OBJECTIVES: To quantitatively describe the sleep characteristics of children with fetal alcohol spectrum disorder, and qualitatively describe the effects of sleep disruption on the affected child and their family.

RELEVANCE: To develop appropriate sleep management strategies for children with fetal alcohol spectrum disorder and their families.

METHODS: A two part design was used. Nine children and their families were recruited from the Clinic for Alcohol and Drug Exposed Children at Children's Hospital in Winnipeg. Each study child was matched with a non-biologically related healthy control child in the same household. The first part of this research was a qualitative study of sleep using actigraphy as a measure of sleep disturbance. Actigraphic parameters were correlated with information from a pediatric sleep questionnaire designed for this study and with a parent maintained sleep log. The second part of the

study consisted of a series of semi-structured interviews with the same families with thematic analysis of the data.

RESULTS: Actigraphic analysis showed significant differences in the mean duration of wake episodes (minutes, $p=0.0072$) and the mean duration of sleep episodes (minutes, $p=0.0064$). The differences in the number of wake episodes was also significant ($p=0.0241$) as was the number of sleep episodes ($p=0.0214$). These data support observably more restless sleep in alcohol affected children. Questionnaire analysis supports a significant degree of concern among families of these children, who identify disrupted and restless sleep patterns, along with daytime behavioural concerns including daytime fatigue and hyperactivity. Alcohol affected children were described as having five times as many sleep related behaviours as control children. Thematic analysis of the interviews supports a significant impact of sleep disruption in families caring for these children, but also supports a high level of commitment to them, particularly when appropriate supports are in place.

CONCLUSIONS: Actigraphic analysis supports significantly disrupted sleep patterns in alcohol affected children with frequent awakenings and greater restlessness in sleep. Families are more likely to identify sleep disruption in alcohol affected children, describing excessive movements in sleep with associated daytime fatigue and hyperactivity. While there is a significant impact of sleep disturbance and related behaviours on families caring for these children, appropriate management and understanding of these problems is important to supporting families in caring for these children.

ACKNOWLEDGEMENTS

This study has been undertaken to understand the sleep behaviours of children with fetal alcohol spectrum disorders, and to acknowledge the unique behavioural challenges they may experience with their families. I am indebted to the families who so generously offered their time and patience with this involved study. I am also indebted to their community agencies who were supportive of their involvement with this work. This study could not have occurred without the generous support and assistance of the Clinic for Alcohol and Drug Exposed Children. This study was generously supported by the Children's Hospital Research Foundation.

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SLEEP CHARACTERISTICS OF YOUNG ALCOHOL AFFECTED CHILDREN: A QUANTITATIVE AND QUALITATIVE ANALYSIS

CHAPTER 1 – INTRODUCTION

1.1 Brief Description of the Research Problem

Alcohol is one of the most common social teratogens. While there are anecdotal references relating to biblical times (1), concerted efforts towards understanding the mechanisms of teratogenicity and the clinical phenotype have only been documented since the early 1970s. The explosion in knowledge since that time has been matched by an evolution in the understanding of associated diagnoses and morbidity. The effects of exposure to alcohol abuse prenatally are variable and may depend on dose, timing, and maternal metabolism, as well as environmental and genetic factors. The associated disabilities persist throughout the lifespan, and include both the primary dysmorphism as well as secondary disabilities related to social and behavioural dysfunction. Early diagnosis and intervention, social stability, and a nurturing environment free of abuse are considered protective factors that are significantly associated with a decrease in secondary disabilities (2).

Sleep disruption is a widely identified, but poorly described, secondary disability associated with prenatal exposure to alcohol. Alcohol affected children are frequently cared for outside their biological home. More than 80% of children with fetal alcohol

syndrome are living in non-biological care situations (2). More than 90% of individuals with fetal alcohol syndrome (FAS) have associated mental health problems (2). The body of literature describing the relationship of behavioural disturbance and sleep disturbance in children with developmental disabilities continues to expand; however, to date, there is little literature specifically describing the sleep patterns of alcohol affected children.

The primary goal of this research was to describe the sleep patterns of young alcohol affected children. The primary quantitative measures have been described through the use of actigraphy. The actigraph is a portable and non-invasive method of motion analysis that describes specific sleep parameters. This method was used to distinguish alcohol affected children from non-affected controls on the basis of these parameters. The actigraphic results were correlated with caregiver reports through the use of a sleep log, and a sleep questionnaire designed for this study.

The second goal of this research was to describe the significance of these disturbed sleep patterns to the child and family dynamic. This was explored using a qualitative interview methodology with thematic analysis. Each family participating in the first part of the study was offered a semi-structured interview designed to explore the qualitative aspects of the child's sleep disturbance, the impact of that sleep disturbance on the family, and the family's approach to coping with that disruption.

1.2 Research Objectives

The hypothesis of this study is that children who have been prenatally exposed to the toxic effects of alcohol show disturbed patterns of sleep that are quantitatively and qualitatively different than non-exposed children. The objectives of this research are:

- 1) To describe patterns of sleep in young alcohol affected children using primary quantitative measurements, specifically achieved through the use of actigraphy.
- 2) To describe patterns of sleep in young alcohol affected children using secondary quantitative measures through caregiver reports, recorded through the use of sleep logs and a caregiver sleep questionnaire.
- 3) To describe the family's understanding of the altered sleep patterns of their alcohol affected child.
- 4) To identify coping mechanisms and supports used by families dealing with sleep disturbance in the alcohol affected child.

CHAPTER 2 – BACKGROUND INFORMATION AND LITERATURE REVIEW

2.1 Fetal Alcohol Syndrome: The Problem and its Context

In Western society, Fetal Alcohol Syndrome (FAS) is now a well-recognized spectrum of dysmorphic and neurodevelopmental features seen in many children exposed to alcohol in utero. Anecdotal descriptions of alcohol affected individuals date back to biblical times (1). However, formal identification of the Fetal Alcohol Syndrome was first proposed in North America by Jones and Smith in 1973 (3). They identified a syndrome of craniofacial malformations, growth retardation, and impairments in intellectual functioning, associated with prenatal exposure to alcohol. Since that time, research toward understanding the effects of prenatal exposure to alcohol has grown exponentially. In 1981, as a result of that research, the Surgeon General of the United States declared that there was no safe amount of alcohol that a pregnant woman could consume (4).

In 1989, recommendations were published from the Fetal Alcohol Study Group of the Research Society on Alcoholism establishing guidelines for diagnosis according to these descriptions (5). According to these guidelines, diagnosis relies on a history of maternal alcohol usage during pregnancy in combination with examination findings of 1) growth retardation (height and weight below the 10th percentile when corrected for gestational age), 2) central nervous system dysfunction and 3) characteristic craniofacial abnormalities including at least two of microcephaly, microphthalmia or

short palpebral fissures, poorly developed philtrum, thin upper lip, and maxillary hypoplasia (6). The guidelines were revised in 1996 and published by the Institute of Medicine in their document outlining diagnostic criteria for Fetal Alcohol Syndrome (FAS), Partial FAS (formerly Fetal Alcohol Effects), and Alcohol Related Neurodevelopmental Birth Defects (ARNDD) (7). Clarren et al. further refined the criteria into a four-digit diagnostic code, intended to standardize individual diagnostic descriptions by exposure, dysmorphology, cognitive function, and behaviour (8).

The number of children prenatally affected by alcohol in Canada is not well documented. Government statements on prevalence of alcohol related birth defects estimate a rate of 1-3 per 1,000 live births, which is consistent with other industrialized countries (9). In the United States, the number of children under 18 with an alcoholic parent has been estimated at 6.6 million (10). The total number of children of alcoholic parents in the United States has been estimated at 22 million, therefore, 1 in 8 children in the States is a child of alcoholic parents (10).

The prevalence of children prenatally affected by alcohol exposure varies widely depending on diagnostic criteria used, diagnoses included, methods of case ascertainment, and the population surveyed (11). In fact, it has been observed that the prevalence rates in the literature “vary more than a hundredfold” (12), depending on a number of factors including case definition and methodology. These rates are not often well understood, and are often difficult to obtain (13). Rates often vary with the population identified for study, suggesting possible ascertainment bias. A

population based database study in Saskatchewan in 1996 yielded a standard, but arguably underestimated, prevalence rate of 0.5 cases per 1,000 live births that included only cases of FAS (14). Local studies of remote northern communities have identified rates of FAS from 16% to 25% (15)(16;17), and as high as 190 per 1,000 in an unpublished report by Asante et al., 1985 (12).

The most widely quoted figures for FAS incidence are 1-2 per 1,000 live births (11). Population based studies vary widely in their estimates of incidence from 0.97/1,000 live births (18) to as high as 46 per 1,000 live births in a survey of children in Northern British Columbia (19). Asante and Robinson have also noted that both the incidence and prevalence rates of Fetal Alcohol Syndrome in British Columbia are higher in native children as compared with non-native children (19), concurring with previous study (17). Similar patterns have been identified in the United States, where estimates of incidence of children prenatally affected by alcohol varies from 0.5 to 3 births per 1,000, and have also been found to be higher in select populations (20).

In Manitoba, data from the Clinic for Drug and Alcohol Exposed Children (CADEC) for the 3 year period April 1, 2000 to March 31, 2002 show that an average of 354 children per year are referred for evaluation of possible alcohol related diagnosis (21). These children are referred to the Clinic for Alcohol and Drug Affected Children (CADEC) at Children's Hospital in Winnipeg, where a complete diagnostic database is kept. From the received referrals, an average of 191 children per year have been

triaged for assessment through the clinic; 46% of these children have received an alcohol related diagnosis (21).

The cost estimates of caring for a child with FAS are enormous. In Canada, the estimated lifetime costs per child with FAS are now estimated at \$3-6 million dollars (22). The additional social costs of increased health care, special education, social services and criminal justice costs are estimated to be another \$3 billion per year for this group of children (22). In the United States, total costs have been estimated as high as 10 billion dollars per year, not including the costs of foster care (10).

In Canada, many alcohol affected children are placed into foster care in their early years. Habbick et al “found that children entered foster care at two years of age on average, and remained in foster care for an average of over five years,” often experiencing multiple moves (14). Previous work has consistently described high rates of foster care and placement (23;24) The literature on the general effects of foster placement on children’s behaviour is extensive. It has been observed that medical complications may also have an impact on early instability in the child’s living situation (25). Prenatal exposure to alcohol and other drugs exerts additional health and caregiving needs (26). While alcohol is found to exert an independent effect on neurodevelopment (27;28), other studies have reinforced the importance of early long term stability, finding that the risk for adverse outcomes in children with FAS may be increased by multiple placements (29).

Determining the specific needs of this population group is an important goal of public prevention and intervention programs (30). Intersectoral national strategies in each area of prevention, identification, and intervention have been organized and described in key documents published by Health Canada in concert with the Canadian Centre of Substance Abuse (CCSA). Many of these strategies have been outlined in a key situational analysis report published in 2001 (30). Specific research strategies for the purposes of program planning and service delivery are organized and described by province in this document. Nonetheless, there is recognition of limitations in both research and support services available to alcohol affected children and their families (22).

2.2 The Morbidity of Fetal Alcohol Syndrome

Behavioural disturbances are well documented in children who have been prenatally exposed to alcohol. These psychiatric and behavioural manifestations have been the subject of numerous long term descriptive studies since the 1970s. Affected children experience a wide range of cognitive and behavioural effects, including disorders of attentional and motor control, poor habituation, poor state regulation, emotional disorders, and abnormal habits and stereotypies (6;31-34). Many authors have contributed to the delineation of the fetal alcohol phenotype. Streissguth and Steinhausen have each published extensively on the longitudinal neurodevelopmental

consequences of prenatal alcohol exposure (2;23;27;35-44). Other authors have described specific learning disabilities and patterns of mental retardation (29;45).

These patterns of central nervous system dysfunction are associated with structural brain abnormalities including microcephaly, cerebellar hypoplasia and dysgenesis, abnormal neuronal and glial malformations, and abnormalities in the basal ganglia (46;47). Much of the central nervous system dysfunction is clinically observed in the demonstration of a variety of neurological "soft signs" including impaired fine motor or gross motor skills, learning disabilities, memory deficits, attentional deficits, poor impulse control, and problems with language, abstraction, and judgment (48).

In 1998, Streissguth et al published their "Fetal Alcohol Behavior Scale" (FABS), intended to describe "the behavioral essence" of fetal alcohol syndrome (FAS) and fetal alcohol effects (FAE) (49). The scale is intended to describe a "behavioral phenotype" of alcohol affected (46) children, felt to be reflective of fetal alcohol itself rather than the "behavioral consequences of being raised in an alcoholic home" (p.332). The earlier "Personal Behaviors Checklist" of alcohol related descriptors includes sleep as one of 68 defining and robust characteristics of the final behavioural phenotype (40). A previous longitudinal study describing a cohort of children with FAS not only describes a significant frequency of sleep disorder in these children compared with controls ($p < 0.05$), but a significant increase in those rates over time, showing a greater change with time than even the hyperkinetic disorders (6). Thus, there is face validity in the further study of sleep disturbance as a significant characteristic of this population.

2.3 Physiological Basis for Alcohol Effects

A number of studies have attempted to describe the physiologic basis for the teratogenic effects of alcohol in the fetus. Alcohol is known to readily cross the blood-brain barrier through the placental circulation. Four main processes have been identified in the neuropathology of FAS: excessive neuroapoptosis or programmed cell death, impaired cellular proliferation, disruption of cell migration patterns, and inhibition of nerve growth through disruption of neurotransmitters and their receptors (29). Given that alcohol levels in the infant are comparable to those of the mother, it is has also been postulated that the withdrawal process from alcohol itself may also contribute to its teratogenicity, perhaps through receptor-mediated excitotoxicity (50).

There is evidence that alcohol exposure early in development during periods of rapid brain growth has a direct effect on the production of neurotransmitters and adversely effects communication between different areas of the brain (51). Neurotransmitters are generally classified as either excitatory or inhibitory (ie. either increasing or decreasing the firing rate of the receiving post-synaptic neuron) and govern, in various ways, normal brain function.. Substances which interfere with these transmitter systems have the potential to significantly effect brain function and behaviour. Most recently it has been postulated that alcohol's teratogenicity is linked to its effect on glutamate receptors and consequent GABA potentiation (52). GABA is a major inhibitory neurotransmitter that has also been implicated in the induction

and maintenance of slow-wave sleep (53). Glutamate also has a role in cortical activation and wake states (53). Animal studies investigating the effects of alcohol on other neurotransmitter systems have hypothesized a resulting “hypofunction” of the dopamine system that may have long term neurobehavioural effects (54). The role of neurotransmitters in the clinical phenotype of fetal alcohol syndrome is just beginning to be understood. Similarly, the abnormalities in neurotransmission in fetal alcohol syndrome, and their etiologic role in the sleep characteristics seen in alcohol affected children, remains unclear.

Recent work has used neuroimaging to study children with FAS using MRI and SPECT scanning (13;55;56). Morphological anomalies described by these authors include cortical atrophy, dilated ventricles, corpus callosum hypoplasia, cerebellar atrophy, and Arnold-Chiari malformation. Left-right asymmetry of the hippocampus, the area associated with memory, and decreased perfusion in the frontal area associated with behavioural inhibition and control, has been described, using morphometric and perfusion techniques (57). This work supports the anatomic abnormalities resulting from alcohol exposure, in areas of the brain involved in learning, attention, and behaviour.

More recent work has begun to investigate the effects of early prenatal alcohol on the regulation of circadian rhythmicity and the long term consequences on behaviour. Alcohol exposure has been found to decrease levels of neurotrophins (58), and has been linked to disturbances of sleep wake patterns (29;59). Animal studies on rats

exposed to alcohol in the early postnatal period have shown a shortened circadian sleep-wake cycle, as well as abnormal circadian neurotrophin expression in the suprachiasmatic nucleus, which regulates circadian rhythmicity (51). The resulting behaviour of the exposed rats was marked by highly fragmented sleep-wake intervals, with reduced nighttime levels of neuropeptides, suggesting an abnormality of circadian regulation (51). This initial work on the influence of alcohol on the rhythmicity of internal body processes in animals underscores the need to correlate rat studies with clinical human observations.

2.4 Physiology of Sleep in Healthy Infants and Young Children

It is important to describe patterns of normal sleep in the healthy infant to understand the abnormalities seen in children with neurodevelopmental disabilities. The clinical relevance of neonatal sleep studies in this population rests on the assumptions that abnormalities in sleep state organization, sleep state rhythm, or in individual measures reflect pathologic central nervous system functioning or maturational lags in CNS development.

Understanding of the physiologic differences in sleep between children and adults has only emerged in the last 40-50 years. Sleep state organization in infants through childhood varies from that of adults in a developmental fashion (53). The maturation of electroencephalographic (EEG) patterns during sleep from pre-conceptual to post-conceptual ages has been described by a number of authors since the early 1960s, and

age-specific patterns have been described that are correlated with the sleep phase. Eye movement and body movement patterns have also been described. These patterns are felt to reflect developmental states of neurological maturity.

The normal sleep and wake states of infants and children follow a developmental maturational course. Direct behavioural observations of young infants have identified states of alert, waking (non-alert), activity, fussing or crying, drowse or sleep-wake transition, active sleep, quiet sleep and unclassified sleep (60). These states are individually consistent, as well as dependent on dynamic interactional patterns between infant and mother (60;61). Additional study of infant sleep has been able to further describe these maturational patterns in sleep, as well as environmental factors affecting sleep. Circadian rhythmicity, reflecting intrinsic behavioural state control, is established in the first few weeks of postnatal life (61;62). Variability in these states appears to be characteristic of immature sleep patterns (63), with a developmental organization of this variability noted between 3 and 4 months of age (64). A gradual increase in slow wave sleep and a decrease in indeterminate sleep develops with increased neurological maturity (65).

The organization of internal sleep cycles in healthy infants thus follows an organized developmental pattern. The development of organized patterns of sleep is generally felt to be reflective of other neurodevelopmental self-regulatory capabilities. These developmental patterns are a function of the individual biology of the infant, as well as being impacted by external environmental influence.

The sleep of older infants and toddlers continues to follow developmental maturational patterns. During the preschool years, there is a well described decrease in the amount of sleep required from an average of 13 hours of sleep per night at age 2 years, to 11.5 hours at age 4 years and 9.5 hours at age 6 (53;66). Napping similarly declines, and is generally eliminated by 4 to 5 years of age (66). Surveys of sleep disturbances in this age group shows that night awakenings and settling difficulties are common sleep disturbances that reflect normal developmental processes in this age group (67;68). These sleep disturbances may also reflect intrinsic neuropsychological differences such as variations in sensory thresholds and self-regulatory abilities (69-71), as well as environmental factors such as family stress and maternal responsiveness (66;70).

The impact of sleep disturbance on developmentally normal young children has also shown significant relationships between daytime behaviour management problems and the presence of sleep disturbance (66;68;72). As may be expected, daytime fatigue complaints are common in young children with sleep disturbances (68;72). Young children with persistent sleep disturbances are also significantly more likely to demonstrate externalizing behaviour problems such as tantrums and behaviour management problems (73).

2.5 Sleep Disturbance in Children with Developmental Disabilities

Sleep disturbance is also described in neurodevelopmentally challenged children, with a significant impact on daytime behaviour. Sleep problems are highly prevalent in this group of children with reported prevalence rates of up to 80% (74-76).

Clements and his colleagues were some of the earliest researchers to study the sleep of children with developmental disabilities (77). In their study of 155 children with developmental disabilities, sleep problems were identified by one third of parents, though this number decreased with age. The impact of sleep disorders on these children was significant. Frequent night awakenings were positively correlated with self-injurious behaviour, and, when combined with reduced total hours of sleep, there was a positive relationship with tantrums and destructive behaviour (77). Piazza et al (1996) used direct observations of sleep in a clinical setting in 51 children with developmental disabilities (78). They identified significantly less total sleep, as well as abnormal measures of "appropriate sleep," in these children compared to same aged developmentally normal peers. Wiggs and Stores have studied extensively the sleep and behaviour of children with developmental disabilities (75;79). Specific behaviours correlated with sleep disturbance include irritability, hyperactivity, non-compliance, and aggression (75). These authors' work also points to the need to objectively measure the sleep patterns of these children and control for the multiple confounding effects of environmental factors.

The sleep of developmentally challenged children exposed prenatally to substances of abuse has only recently begun to be described. The sleep patterns of infants exposed to cocaine, for example, has been studied by a number of authors (80;81). As is clinically apparent, these infants show abnormalities of state regulation, which is also reflected in abnormalities of their sleep architecture. These infants demonstrate highly disruptive sleep patterns that are significantly different from controls. These patterns include more wakefulness and more frequent arousals during active sleep, as well as a tendency towards a higher proportion of active sleep compared with quiet sleep (80). The overall spectral power of the EEG with its cortical correlations are also reduced (81). The cardiac and respiratory patterns during sleep in cocaine exposed neonates have also been studied and show significant correlations between sleep state effects and heart rate relative to controls (82).

The sleep of children exposed prenatally to marijuana has also been described in a single report (83). In this longitudinal prospective study, children were followed to age 3 with assessments at fixed points. Polysomnography at age three showed significantly disturbed sleep, with an increase in arousals, more awake time after sleep onset, and reduced sleep efficiency, when compared with healthy non-exposed controls.

The literature on children with developmental disabilities supports the importance of understanding sleep disturbances in individual diagnostic groups. In children who have been affected by prenatal exposure to substance abuse, the literature is growing,

documenting the neurological impact of the toxic exposure, reflected in abnormalities of regulation and state organization. To date, there is no literature on the sleep of preschool children who have been diagnosed on the fetal alcohol spectrum.

2.6 Effects of Prenatal Alcohol Exposure on Sleep Patterns in the Fetus

Novel investigations of the sleep-awake patterns in newborns of mothers who drank during pregnancy was undertaken in the late 1970s and 1980s. These studies laid the groundwork for continued work in the 1990s on the developmental sleep characteristics of these infants. Study of the impact of these sleep characteristics on neurobehavioural patterns in alcohol exposed infants is only recently being developed.

Havlicek, and Childiaeva (1976) at the University of Manitoba, were the first to describe the EEG characteristics of infants of alcoholic mothers, noting significantly disorganized and hypersynchronous patterns (84). This preliminary work was followed in 1977 by a larger study to further describe these patterns in each stage of infant sleep, and compare them to those of healthy non-exposed infants. Infants of alcoholic mothers showed pathologically hypersynchronous patterns across all stages of sleep with significantly higher power than control values (85).

Rosett et al (1979) expanded on this work, attempting to demonstrate a dose response effect on sleep and state regulation in the neonate prenatally exposed to alcohol through a crude stratification of maternal prenatal alcohol intake (86). They studied 31 infants, stratifying them into three groups: infants born to mothers who drank "heavily" versus those who modified their drinking versus a control group. The infants exposed to "heavy" prenatal alcohol consumption were shown to demonstrate more disrupted sleep patterns, with a larger proportion of quiet sleep episodes interrupted by awake or unclassified epochs. They were more restless, and showed more frequent major body movements. This study not only supported the disrupting neurological effects on infants of heavy prenatal maternal consumption of alcohol, but also ventured to suggest that therapy of heavy drinking during pregnancy could improve physiological competence of the newborn to regulate sleep-awake states (86).

Interest in the effect of alcohol on the developing brain continued in attempts to further quantify alcohol's toxicity on neonatal state regulation. Chernick's group at the University of Manitoba, continued to perform a number of electroencephalographic studies to describe the effects of prenatal exposure to alcohol on the developing brain. Their 1983 work analyzed computerized electroencephalograms of infants of mothers who drank versus non-drinking controls (87). The neonatal electroencephalogram (EEG) of the infants exposed to alcohol alone showed significantly hypersynchronous or disorganizing effects that were not seen in those whose mothers smoked. Their data were the first to confirm a specific

toxic effect of alcohol on the fetal brain. Follow-up work by Chernick's group demonstrated that the disrupting effect of alcohol on state regulation was prolonged and was not related to alcohol withdrawal (88). Follow-up work further explored the effects of varying amounts of alcohol exposure on the neonatal polysomnogram, showing effects on both REM and quiet sleep independent of gestational age (89). This led to further work on the future neurodevelopmental implications of alcohol related neonatal state disorganization. Predictive correlations were able to show that the increased power of the electroencephalogram at birth correlated well with subsequent neurodevelopmental disorders of motor and mental development (90).

Recent animal studies have focused on the specific toxic effects of prenatal alcohol exposure on circadian rhythmicity and sleep, as functions of biological regulation. Work on the influence of alcohol exposure on the circadian clock remains highly speculative. It has been shown, for example, that adult rats exposed to alcohol early in brain development show a shortened and more fragmented sleep-wake cycle, associated with dampening in neurotrophic growth factors associated with circadian behaviour (91). The most recent work has attempted to quantify sleep characteristics in a rat model of fetal alcohol syndrome (92). This study has demonstrated significant reductions in REM (rapid eye movement) sleep in the alcohol exposed female rats; the reason for the gender difference was not clear. This study provides supportive evidence for a toxic effect of alcohol on sleep architecture in this rat model.

2.7 Summary

The neurodevelopmental characteristics of children with Fetal Alcohol Syndrome have been widely described, and reflect abnormalities in organizing, self-regulatory, and hyperkinetic behaviours. These characteristics reflect neurological abnormalities at both anatomical and biochemical levels. Sleep is a well-recognized marker of neurological maturity and pathology. Despite this, the sleep characteristics of children prenatally exposed to alcohol have not been well described. The purpose of this study was primarily to describe quantitatively, using actigraphy and sleep logs, the sleep characteristics of alcohol-affected children compared with household matched controls. This study also qualitatively described the impact of those sleep patterns on the child and their family using a semi-structured interview technique, to add richness to the quantitative data.

CHAPTER 3 -- METHODS

3.1 Subjects

3.1.1 Recruitment

Study patients were selected consecutively from the Clinic for Alcohol and Drug Exposed Children (CADEC) formerly referred to as the Child Development FAS Clinic. CADEC is a multidisciplinary diagnostic clinic run with the cooperation of the sections of Child Development and Genetics and Metabolism at Children's Hospital in Winnipeg. Children referred to the clinic from the community are assessed and diagnosed as appropriate. Children who are seen through the clinic, are diagnosed by a multidisciplinary team, including a developmental pediatrician and a geneticist. Medical and social history is available through a systematically collected database of information. Each year, CADEC sees an average of 191 children for diagnosis; of these children, 6% receive a diagnosis of FAS, 16% receive a diagnosis of Partial FAS, and 24% receive a diagnosis of ARNDD (Alcohol Related Neurodevelopmental Deficit). The remainder are either deferred (10%), normal (10%), or fall under another diagnostic label (34%) (21). Children were recruited for the study with the assistance of clinic staff and physicians. The foster parents of a single patient who had previously been diagnosed through the clinic contacted the Child Development Clinic for participation in the study. All patients who qualified for the study and were approached for participation, consented. A copy of the poster and the consent forms are appended (Appendices A,B,C).

Children included were those between 1 and 8 years of age, with an alcohol related diagnosis formally made in the clinic. Patients identified were medically stable, defined as without acute illness, or cardiorespiratory compromise. They were also “socially stable,” operationally defined as being in a single or biological placement, or having no new placements in the past 12 months. Patients were excluded if they were on chronic medication such as stimulant medication, anticonvulsant medication, or psychoactive medication. The presence of a child to act as control in the same household was also required, to control for both alcohol effects as well as sleep environment and parenting approach to sleep. The control child was to be similar in age (loosely defined), healthy, on no medication, with no alcohol related diagnosis, and no sleep concerns. One control child was required for each study child.

The final total sample consisted of nine alcohol affected children, and nine control children. The study originally intended to identify ten patients with each diagnosis (i.e. ten with FAS, ten with Partial FAS, and ten with ARNDD), and thirty controls. Achieving these numbers while meeting our own inclusion and exclusion criteria proved challenging. The limiting factor proved to be the presence of a child to act as control in the household. All of the foster families contacted were interested in participating. Many of these families foster more than one child with multiple problems including alcohol effects, attention deficit hyperactivity disorder, or psychiatric disorders. Many families with biological children choose to foster after their own children are grown and therefore would not have suitably aged control children in the household.

3.1.2 Characteristics

There were no significant differences in the ages of the study patients or their controls (See Table 3.1 below).

Table 3.1: Age Characteristics of Study Children: Alcohol-Affected vs Control

Study Patients	Alcohol Group (months)	Control (months)
1	46	20
2	83	46
3	33	93
4	58	96
5	43	80
6	61	49
7	74	71
8	69	54
9	98	59
Mean age (months)	62.78	63.11
Lower 95% CI	46.93	24.43
Upper 95% CI	78.62	81.42

The average age of the study patients was 62.78 \pm 15.85 months; the average age of the control patients was 63.11 \pm 18.77 months. All of the study patients were in foster care; most of these children had been in care since birth or shortly after birth. Children had experienced an average of 3 foster placements with a range of 1 to 8 placements. The average time in placement was 47.50 \pm 10.12 months (See Table 3.2 below).

Table 3.2: Time in Current Placement of Alcohol Affected Children (months)

Study Patients	Alcohol Group (months)
1	43.50
2	72
3	33
4	58
5	36
6	60
7	38
8	39
9	48
Mean time in placement (months)	47.50
Lower 95% CI	37.38
Upper 95% CI	57.62

Seven of the foster children had been placed less than three times; one placed six times, and the last placed 8 times. All children involved in this study had been in their most recent placement over one year. The child who had experienced eight placements had been stable in his current situation for over past two years. Six of the nine control children were biological children of the foster parents. The three remaining control children were foster children, but healthy and unrelated to the study children.

The developmental quotient (DQ) of each patient was obtained from the CADEC database. The developmental quotient reflects a combination of developmental age scores in adaptive, language, gross motor, fine motor, and personal/social areas. The score is calculated by the developmental pediatrician following developmental

assessment. The average DQ of the alcohol affected patients was 86.2 +/-6.49, which is within the low normal range (normal 100 +/-30) (see Table 3.3 below).

Table 3.3: Developmental Quotient (DQ) in Alcohol Affected Study Children

Study Patients	Total Alcohol Group
1	85
2	89
3	90
4	72
5	100
6	90
7	85
8	90
9	75
Mean DQ	86.22
Lower 95% CI	79.73
Upper 95% CI	92.72

$$\text{*Developmental Quotient} = \frac{\text{developmental age}}{\text{chronological age}} \times 100$$

3.2 Quantitative Measures

3.2.1 Actigraphy

Actigraphy is a method of motion detection and analysis that is used as a portable and non-invasive measure of sleep. Actigraphy has been found to compare favourably with polysomnography, with an 85-90% agreement rate, and has been found to distinguish between sleep disturbed and control children (93). It has also been found to have good face validity and good reliability (93). Early work using actigraphy described a good relationship between levels of nocturnal activity and the sleep-wake state (94). Good agreement has been described between actigraphy and sleep logs in

the identification of sleep/wake disorders and the measurement of changes in sleep patterns over time (95). The use of actigraphy in pediatrics has also been documented as an important correlative objective measure, particularly when used with subjective measures such as sleep logs and sleep diaries (93;96).

Actigraphs are micro-processor controlled portable piezoelectric monitors with a programmable time base. They are about the size of an adult wristwatch, and quite lightweight (approx. 40g). They are externally worn on either the wrist or ankle with minimal discomfort, and are therefore a useful tool in the ambulatory evaluation of sleep disorders in pediatrics. The actigraphs used in this study were Basic Mini-Motionloggers from Ambulatory Monitoring, Inc. These actigraphs have a fixed sensitivity at 2-3 Hz. Their piezoelectric beam sensor detects accelerations greater than 0.01g force. Cumulative movement counts are stored in the sensor's memory each minute, available to be downloaded and analyzed. The mechanism is encased in a metal, waterproof case; parents were given written instructions as to its proper placement and application (see Appendix D). The actigraphs were worn for a period of 7 days as suggested by Acebo {93} to allow for observation of shifts in sleep patterns that may occur on weekends (97;98). Each child, alcohol affected and their household matched control, wore an actigraph for the same 7 day period.

The actigraphic mechanism has a 32K memory with a sampling rate of 10 Hz. As suggested in the accompanying manual, the actigraphs used in this study were initialized to employ zero-crossing mode using an auto actigraph interface with a built

in comparator (a magnetically generated calibration signal for comparison of performance over time and between units). Data were transferred to a PC computer using an external interface unit from Ambulatory Monitoring, Inc. Data were extracted using the ACT operational software provided by Ambulatory Monitoring, Inc. The raw activity data were inspected and compared against sleep log data to ensure accuracy of in bed times, out of bed times (rise times) and wearing of activity monitor reliability. Bad data was trimmed, and sleep periods were identified as “down intervals” using the ACTION-W2 version 2.0 software (1999) also provided by Ambulatory Monitoring, Inc (99). Summary analyses were completed also using the ACTIONW2 software. The sleep estimation algorithm used was the Sadeh adult algorithm (100) based on personal e-mail communication with Dr. Sadeh, 2000.

3.2.2 Actigraphic Statistical Analysis

Each descriptive statistic computed by the accompanying software was examined for this study. The original intent was to distinguish among the three alcohol related diagnosis (FAS, partial FAS, and ARNDD). Unfortunately, total study numbers were small, leaving only a couple of children in each group. It was decided therefore to analyze the whole group of alcohol affected children versus their controls. Descriptive statistics as outlined in the manual were calculated based on the period from sleep onset to wake onset, defined as the period from the time the parent indicated bedtime, to the time the parent indicated the child was awake. The descriptive statistics calculated by the actigraphic AW2 software are described in the AW2 manual as follows:

Descriptive Statistics*:

Duration	Minutes from start to end of interval
Activity mean	Mean activity score (counts per minute)
Activity median	Median activity score
Activity standard deviation	Standard deviation of activity score
Wake minutes	Total minutes scored as Wake
Sleep minutes	Total minutes scored as Sleep
Percent sleep	Percent minutes scored as sleep
Sleep efficiency	(100*sleep minutes/(O-O duration))
Sleep latency	Minutes to 1 st 20min block with >19min sleep
Wake after sleep onset	Wake minutes during O-O interval
Acceleration index	Change in activity rate during interval AI=2p-1 p= proportion of interval required for 50% of total activity to be completed
Activity index	% epochs with >0 activity score
Wake episodes	# of blocks of contiguous wake epochs
Mean wake episodes	Mean duration of wake episodes (minutes)
Long wake episodes	Wake episodes >5minutes
Longest wake episode	Duration of longest wake episodes (minutes)
Sleep episodes	# of blocks of contiguous sleep epochs
Mean sleep episode	Mean duration of sleep episodes (minutes)
Long sleep episodes	Sleep episodes >5minutes
Longest sleep episode	Duration of longest sleep episodes (minutes)

*Definitions from Action-W2 Users Guide (99)

The data were analyzed using Graphpad Prism software and SAS (SAS 8e for Windows). Data for the group of alcohol affected children and the non-affected control group were analyzed using a repeated measures analysis of variance using the SAS GLM procedure. All reported p values are based on two sided test, and considered significant at $p < 0.05$. Each night was entered as individual units of data,

alcohol affected (N=63) versus control data (N=61), with two nights of control data not available as the parent forgot to put the actigraph on the child. The repeated measures analysis of variance was carried out with the assistance of the Biostatistical Consulting Unit, University of Manitoba.

3.2.3 Pediatric Sleep Questionnaire

The sleep questionnaire used in this study was developed by the author for use in this specific population i.e. preschool children between 2-6 years of age who are alcohol affected and therefore have a developmental disability (see Appendix E). The questionnaire has not been validated. However, the questions themselves have face validity and compare well with other pediatric questionnaires available at the time of this writing. There are a number of sleep questionnaires designed for use in children (68;101-105). However, at the time of data collection for this study, there were no instruments considered appropriate for use in preschool alcohol-affected children in foster care. Many of the above instruments are either self-report questionnaires, or are more appropriate for use in developmentally normal children. The children participating in this study are largely of preschool age, and therefore the questionnaire is completed by their caregiver/foster parent. Sleep history data are limited to the experience of the foster parent while caring for the individual child, and include only limited past history or family history. The Children's Sleep Behavior Scale was standardized on children with developmental disabilities, but provides insufficiently detailed data (101). The Children's Sleep Habits Questionnaire has demonstrated good test-retest reliability and content validity in distinguishing healthy children with

sleep disorders. However, it has not been standardized for use in children with developmental disabilities (106).

The questionnaire used in this study was developed for this study and has not been formally standardized. Questions were developed to address demographic and historical information on each child, as well as collect data on sleep routines, daytime sleep behaviours, night time sleep behaviours, parental responses to awakenings, previous sleep investigations and treatments. The specific questions include a range of behaviours that have been previously documented in children with developmental disabilities. The questionnaire takes approximately 15-30 minutes to complete. All the questionnaires submitted were completed and returned, giving a 100% response rate.

3.2.4 Questionnaire Statistical Analysis

Questionnaire results were compiled and analyzed using two-tailed Fisher's exact t-test (Graphpad Prism 3.03 software) to look for significant differences between the alcohol- affected group and the controls. The relative risk of each outcome category was calculated. Where the relative risk could not be calculated, usually because of a zero value for the outcome of interest in the control group, the odds ratio was used as an approximation of the relative risk

3.2.5 Sleep Log

The sleep log used in this study was developed by Dr. Henry Shapiro and is available for reprint on the internet site of the Society for Developmental and Behavioral Pediatrics (See Appendix F). This sleep log was used because of its simplicity and brevity. In general, sleep logs are used in clinical practice and are felt to show good agreement with videotapes of children's sleep (107). The purpose of the log was to provide a clinical impression of the child's bedtime, sleep onset, nighttime awakenings, wake time, and arising time. There is a comment section for each night to record any specific concerns, such as illness, which may impact upon the child's sleep that night. This information was also used as a correlative measure against the information obtained using actigraphy. The sleep log was kept for each day the actigraph was worn. Data from the logs were used to ensure accuracy and consistency with actigraphic data, as well as to facilitate trimming of actigraphic data prior to analysis.

3.3 Qualitative Methods

3.3.1 The Semi-Structured Interview

The narrative interview was used to offer subjective insight into the impact of childhood sleep disturbance on family functioning. The goal of the interview was to develop a narrative account of the needs and coping strategies of families who are caring for a alcohol affected child with sleep disturbance. A list of guiding questions is appended (See Appendix G). Questions were kept open-ended in order to guide,

but not direct the interview. Interviewing was often guided by themes brought up by the families themselves.

All interviews were tape recorded and then transcribed. Tape recording was undertaken to ensure authenticity, and transcription facilitated thematic analysis. Field notes made during the interview provided additional context of the interaction such as setting, non-verbal communication, and external events (e.g. tending to a child). Additional field notes allowed for reflection on the data gathering process as well as recording immediate thoughts and impressions about the interview itself. Every effort was made to ensure confidentiality with regards to each family. Each original recording and transcription has been kept in a locked and secure area, and will be destroyed on publication.

The interview participants were the foster parents of the alcohol affected children studied in the quantitative portion of this research. Each set of foster parents was contacted following collection of the quantitative data. At this time, the purpose of the study, the length of the interview, and the procedure of the interview was explained. Of the nine original families, five consented to be interviewed, three declined, and one was unable to be contacted. For those parents who were agreeable to the interview, consent was obtained from Winnipeg Child and Family Services. A copy of the consent form is appended (See Appendix C). Field notes both during and after each interview were kept as needed to record observations such as setting, body language, emotion, or interruptions.

Some demographic data were obtained about each family, including members of the household, ages and genders of children, and length of current placement. Open-ended interactive interviews were conducted to develop an account of the family's experience of their child's sleep. The topic was initially approached broadly by the question "Tell me about how your child sleeps." Possible focusing questions included "How did your child sleep as a baby," "Has their sleep changed over time," and "Is their sleep different than your other children's sleep." The interviewer then guided discussion in the following areas:

Does your child nap during the day?

Does your child seem tired during the day?

Can you relate your child's sleep and their behaviour?

Do you feel their health has been affected by their sleep patterns?

Do you feel your health/sleep has been affected by their sleep patterns?

Do you feel your parenting has been affected by their sleep? Your sleep?

What techniques/approaches have you tried to help your child sleep?

What has worked? What hasn't?

What would help you cope with this sleep problem?

Throughout the interview, specific probes were used as required to refine further discussion. The interview closed with an overall assessment by the foster parent of factors that supported their coping, and suggestions they would offer to other families dealing with similar challenges.

3.3.2 Interview Analysis

All interviews were audiotaped and then transcribed for the purpose of data analysis. Data analysis was conducted by hand, given the small number of interviews. All interviews were checked for gaps once transcribed to identify any areas that may have been omitted. Categories, codes, and themes were identified within each interview. Categories were developed into codes and then compared against categories and codes from other interviews. As increasing data were collected, linkages among codes were identified, and themes developed. Data were considered saturated when no new themes emerged.

3.4 Ethics Approval

Ethics approval for each part of the study, quantitative (#E99:359) and qualitative (#H2000:083), was obtained from the Health Research Ethics Board, Bannatyne Campus, of the University of Manitoba.

3.5 Summary

This study was completed in two parts, a quantitative portion using actigraphic analysis of sleep parameters coupled with a sleep questionnaire and sleep log, and a semi-structured interview portion. The data from each part of the study were complementary and enriching. The analysis was intended to provide specific detail regarding sleep parameters in the alcohol affected child, as well as to provide a family perspective on the impact of sleep disturbance to the family.

CHAPTER 4: QUANTITATIVE RESULTS

4.1 Actigraphic Results

Actigraphic data were provided by each of the nine subjects for seven nights, and for their nine controls for the same seven nights, with one exception where data were collected for only five nights on a control child. This provides a total of 63 nights of data collection for the alcohol affected group and 61 nights of data for the control group. The one control patient data collected for only 5 nights was due to the parent forgetting to apply the actigraph for two nights. All of the remaining data were retrievable without difficulty. Sleep log data was simultaneously collected for each child.

4.1.1 Repeated Measures ANOVA

The repeated measures analysis of variance showed a number of significant differences between the alcohol affected and control groups (see Table 4.1 below).

Table 4.1: Summary of Actigraphic Data – Repeated Measures Analysis of Variance for Alcohol Affected children vs Controls

Sleep parameters	Alcohol Group N=63 Mean +/- SEM	Control Group N=61 Mean +/- SEM	F value	P value	P value summary (significance p<0.05)
Total duration (min)	658.2+/-6.8	656.5+/-8.1	0.03	0.8697	NS
Wake Minutes (min)	137.0+/-5.7	147.6+/-8.4	0.98	0.3274	NS
Sleep Minutes (min)	521.2+/-7.3	508.9+/-7.6	1.68	0.2012	NS
Percent Sleep	79.2+/-0.8	77.9+/-1.1	0.86	0.3590	NS
Sleep Efficiency (%)	86.7+/-0.8	85.9+/-1.1	0.32	0.5736	NS
Sleep Latency (minutes)	40.3+/-4.6	41.3+/-4.3	0.01	0.9383	NS
Wake After Sleep Onset (minutes)	80.2+/-4.9	84.8+/-7.2	0.25	0.6214	NS
Activity Index	53.7+/-1.2	56.0+/-1.4	0.382	0.0561	NS
Wake Episodes (number)	21.3+/-0.8	19.2+/-0.9	5.40	0.0241	*Significant
Mean Duration Wake Episodes (min)	6.9+/-0.4	8.2+/-0.4	7.81	0.0072	*Significant
Number of Wake Episodes >5min	7.4+/-0.7	7.4+/-0.9	0.01	0.9115	NS
Duration of Longest Wake Episode (min)	43.9+/-3.8	51.8+/-3.8	2.77	0.1021	NS
Sleep episodes (number)	21.1+/-0.8	19.0 +/-0.9	5.63	0.0214	*Significant
Mean Duration Sleep Episodes (min)	27.4+/-1.3	34.6+/-3.2	8.08	0.0064	*Significant
Number of Sleep Episodes >5min	10.9+/-0.3	10.5+/-0.5	1.65	0.2040	NS
Duration of Longest Sleep Episode (min)	140.6+/-5.5	157.6+/-11.0	5.55	0.0222	*Significant

Subanalysis for individual diagnoses (FAS, Partial FAS, ARNDD) was not done due to the small numbers in each group; alcohol affected children were compared as a group to the non-affected controls as a group. The total duration of actigraphic analysis was comparable in each of the two groups ($p=0.8768$, no significant difference).

Significant differences between the study group and the control group were seen in mean duration of wake episodes (minutes, $p=0.0072$), number of sleep episodes and mean duration of sleep episodes (minutes, $p=0.0064$). To interpret these data, it was also noted that differences in the number of wake episodes was also significant ($p=0.0241$) as was the number of sleep episodes ($p=0.0214$) in favour of the alcohol affected group. Together these parameters suggest a sleep pattern that is significantly disrupted by frequent awakenings in children who are alcohol affected. Group means describing the duration of longest sleep episodes also reach significance, describing shorter intervals in the alcohol affected group. Repeated measures analysis does show a high degree of within subject variability in each group that may reflect individual or subgroup differences not accounted for by this study. Larger group numbers would be beneficial in further delineating these patterns.

The percent sleep and the sleep efficiency describe two closely related parameters that follow similar patterns in these two groups. The percent sleep reflects the number of minutes scored as sleep as a fraction of the total duration; the sleep efficiency reflects the same proportion only during the subintervals of the down

period felt to reflect the true sleep period (ie. subtracting out the period of sleep latency and any terminal wake period; AW2 Manual). There were no significant differences in the percent sleep ($p=0.3590$ NS) or sleep efficiency ($p=0.5731$ NS) between these two groups. This may reflect similar developmental needs for the total amount of true sleep (ie. the times from sleep onset to sleep offset), notwithstanding the differences in sleep disruption. Similarly, there was no significant difference in the number of wake minutes ($p=0.3274$ NS) or the number of sleep minutes ($p=0.2012$) between the two groups. These are potentially important findings as it is frequently stated anecdotally that alcohol affected children require less sleep than non-affected children.

In summary, alcohol affected children showed a slightly greater tendency than controls to demonstrate more restless sleep as reflected by their increased activity mean, increased number of wake episodes, and shorter individual sleep episodes. This study showed no difference in the total amount of sleep demonstrated between each group. There was large within subject variability in many parameters that may reflect differences in subdiagnoses which this study was not able to address with the number of children participating.

4.2 Questionnaire Results

These questionnaire results are reported in the table below.

Table 4.2: Questionnaire Results

Relative risk and Fishers exact t test (two-tailed) of differences between alcohol affected and non-affected groups

Questionnaire categories	Relative Risk	Confidence Interval 95%	P value	P value summary
Sleep concerns	OR 35.29	--	0.0090	*Significant
Daytime naps	1.000	0.3558 to 2.810	1.3628	NS
Daytime fatigue	7.000	1.067 to 45.92	0.0152	*Significant
Hyperactivity	3.000	1.191 to 7.559	0.0090	*Significant
Bedtime resistance	2.500	0.6448 to 9.693	0.3348	NS
Sleep latency	0.6250	0.3334 to 1.172	0.2941	NS
Transition object	0.7500	0.4474 to 1.257	0.5765	NS
Place of sleep	1.125	0.8929 to 1.417	1.000	NS
Night awakenings	3.000	0.8119 to 11.08	0.1534	NS
Woken by own movements	OR 23.22	--	0.0294	*Significant
Movement in sleep	1.667	0.5584 to 4.974	0.6372	NS
Parental support at night	0.6667	0.2808 to 1.583	0.6372	NS
Sleep aids	OR3.353	--	1.000	NS

Two thirds of the families identified sleep concerns in their alcohol affected children; as anticipated from the inclusion/exclusion criteria, none of the families had sleep related concerns in their non-affected child. The odds ratio for the presence of any sleep related concerns in alcohol affected children is 35.29 in this study. The sleep

concerns identified in the alcohol affected group included talking in sleep (44%), difficulty falling asleep (33%), and daytime sleepiness (11%).

Daytime behavioural concerns were strongly identified in alcohol affected children, and showed significant differences from the control children. Seventy eight percent of the families of alcohol-affected children felt their child showed signs of daytime fatigue; the difference between these groups was significant ($p=0.0152$) with a relative risk of 7.00 for daytime fatigue in children with an alcohol diagnosis. All of the alcohol affected study children were identified by their families as hyperactive during the day, compared with 33% of the control children, a highly significant difference ($p=0.0090$).

Both study and control families described a comparable regular nighttime routine. A little over half of the alcohol-affected children were felt to resist bedtime, compared to only 22% of the control children, but this difference was not significant. Two thirds of the alcohol affected children use a transition object at bedtime, and nearly all the control children have a similar object ($p=0.5765$). One of the alcohol-affected children (11%) fell asleep to the sound of a bedroom fan; none of the other children used any environmental modifications to facilitate sleep ($p=1.000$ NS). All of the children except for one control child, slept in their own bed ($p=1.000$ NS). These observations reinforce the similarities in nighttime environments and routines experience between the alcohol affected children and their familial controls.

Most of the control children fell asleep within 10-20 minutes. However, there was a much wider spread among the alcohol-affected children, evenly distributed from less than 10 minutes (22%), to 20-30 minutes (22%), to over one hour (22%). When these differences were combined to compare shorter (0-20 minutes) versus extended sleep latencies (20-60+ minutes), no significant differences were identified ($p=0.2941$ NS).

Alcohol affected children woke during the night for a variety of reasons, the most significant of which was related to their own movements ($p=0.0294$). Alcohol-affected children in this study were 23 times more likely to awaken because of movement in their sleep. When the other reasons for sleep disturbance were broken down into subcategories, they did not reach significance. Nonetheless, almost half of the children (44%) woke simply to play. Dreams and fears comprised another third of the reasons for wakening, followed by basic needs of toileting (33%) and feeding (11%).

Reported night awakenings were an area of considerable anecdotal difference between study and control children. However, this did not reach significance ($p=0.1534$ NS). While most of the control children (78%) slept through the night, the alcohol affected children experienced frequent night awakenings ranging from once a night to over three times per night. Control children typically woke for toileting (67%), feeding (11%), or occasional fears (11%).

Alcohol affected children were described as having five times as many sleep related behaviours than control children in this small sample. Many of the alcohol affected children talked (56%) or cried (44%) regularly in their sleep. One third of the children were observed to be kicking and hitting in their sleep (22%); a smaller number pick or sniff at bedclothes (11%). One of the alcohol affected children sleepwalks compared with none of the control children. One foster parent identified other unusual movements not otherwise described in the questionnaire. The few sleep-related behaviours identified by parents of control children included crying (11%) and occasional talking (22%).

Parenting responses to both alcohol-affected and control children were similar with regards to responding to basic needs, or keeping the child company as required. There was a slightly greater tendency to respond to alcohol affected children by letting them fall back asleep on their own (56% alcohol affected vs 33% controls). Again, parental responses to both alcohol affected and non-affected children showed no significant differences ($p=0.6372$).

Most of the control children slept 9-10 hours per night (67%), with the rest requiring 11-12 hours per night (33%). Alcohol affected children showed greater variability, with 44% sleeping 9-10 hours, 22% sleeping 11-12 hours, and one third sleeping only 7-8 hours per night. None of the children, alcohol affected or control, had ever been given any medications to help them sleep, nor had any families received any sleep-related counseling.

4.3 Summary

In summary, caregivers of alcohol-affected children in our study were 35 times more likely to identify sleep related concerns in these children than in their non-affected foster siblings. The most significant concerns focused on excessive movements in sleep, with associated daytime fatigue and hyperactivity. Alcohol affected children are 23 times more likely to be woken at night by their own movements, and are 7 times more likely to show associated daytime fatigue. The increased rate of hyperactivity in alcohol-affected children has been well documented in the literature. While frequent night awakenings did not significantly differ between alcohol-affected and control groups, a number of other concerns consistent with childhood parasomnias such as talking or walking in sleep were also described. The numbers in these groups were too small to reach significance. Alcohol affected children show greater variability in their sleep needs, and tended to resist bedtime more frequently, although again this difference did not reach significance. Overall, parenting responses to all children were consistent, and did not vary among the groups.

CHAPTER 5 – RESULTS OF THE QUALITATIVE INTERVIEWS

5.1 Overview of the Thematic Approach

In this descriptive study, a thematic descriptive approach was used to understand the sleep behaviours of alcohol affected children, and their family's response to these behaviours. In keeping with the theoretical constructs of this type of research, this study was based on descriptive methods with inductive rather than deductive outcomes where the researcher is the primary instrument of research (108). The purpose of this approach is to “document salient behaviors, events, beliefs, attitudes, structures, [and] processes” (109). Creswell describes the characteristics of a qualitative research problem as one where the concept is “immature,” and one where the nature of the phenomenon may not be entirely suited to quantitative measures (108).

The purpose of a qualitative component to this study was to describe the family's understanding of the sleep behaviours of their alcohol affected child. By doing so, the intent was to understand the significance of sleep disturbance to the family, and identify direction for intervention. This was achieved through the process of a direct caregiver interview, with open-ended questions addressing both the patterns of sleep experienced by the child, and the family responses to those altered sleep patterns (see Appendix G).

Interviews were transcribed and initially coded into 14 categories: parent perceptions of alcohol affected children, child characteristics, child sleep behaviours, child sleep needs, sleep parameters, self-described parenting styles, parent impressions of sleep and alcohol effects, parent responses to sleep behaviours, effects on parent sleep patterns, effects on family, outside advice given, attempted treatments, community resources utilized, and finally, suggestions to other parents. Thematic categories were derived from these categories, namely: child sleep behaviours, child sleep related needs, parent responses to sleep disturbance, and parent advice to others. Emergent from these themes develops a conceptual framework of sleep disturbance as a function of biology, psychology, and environment, including parenting and community support.

5.2 Thematic Categories

5.2.1 *Child Sleep Behaviours*

A number of nighttime sleep behaviours were identified in common by the children's parents. These include behaviours consistent with dyssomnias and parasomnias. A number of isolated medically related sleep behaviours were also commented upon, but did not form a majority of the concerns.

The most commonly related behaviours included those consistent with sleep-wake transition disorders. These disorders are a type of childhood parasomnia that occur in the transition from wakefulness to sleep (110). They are frequently considered developmental in nature. However, if these behaviours persist or are disruptive, they

may be considered as problematic by caregivers. These behaviours include rhythmic movement disorders, sleep talking, and nocturnal leg cramps. They occur in 5-15% of healthy children, depending on the type of disorder (110). Other sleep behaviours also described as parasomnias include arousal disorders such as sleep terrors or confusional arousals, REM parasomnias such as nightmares or REM behaviour disorders, and other behaviours such as bruxism or sleep enuresis (110).

The dyssomnias are a group of disorders characterized by ineffective sleep. They include disorders such as breathing related sleep disorder, narcolepsy, insomnias of childhood, and circadian rhythm disorders. In this age group, the most commonly experienced dyssomnias include those disorders of initiating and maintaining sleep, described by Anders et al as “protodyssomnias” (110). These are characterized by difficulties falling asleep and staying asleep (repetitive night waking). These are also commonly developmental in nature and are found in up to 40% of preschool children (73).

Parents in this study commented nearly universally upon the presence of both parasomnias and dyssomnias in their children. All of the parents commented upon one or more of the sleep-wake transition disorders. Rocking was commented on by over half the parents.

The only thing I can remember back then is he went to bed well but would rock and take a long time to fall asleep...he usually rocks himself to sleep...up

to half an hour...and he would always pick the same corner of the bed...whether it be on his bed or on the rocking chair... (Interview #3)

Other parents commented on the presence of night terrors:

I remember there was something about night terrors...where he would wake up with the shakes...it was like he doesn't even know that you are there (Interview #7)

General restlessness, talking and movement in sleep was universally commented upon.

I can hear him tossing. Sometimes, I can hear him talking. He will just spurt out some words or whatever he is saying or dreaming about, and you can just hear him banging against the side rails of the bunk bed. (Interview #7)

I used to hear him constantly, just moving all the time...he would mumble and whine or whatever but nothing that I could make out. That's if he wasn't waking up crying or screaming...anywhere from once to two to three times per night. (Interview #1)

He is always making noises. Like, "ummm, ehhhh, ahhh," and chanting and singing. And, then once he got the words, he would sing "Twinkle, twinkle little star" for two hours on end. (Interview #4)

Some families commented upon other self-stimulatory behaviours, felt to be soothing behaviours for the child. These behaviours were used at bedtime, as well as throughout the day.

...he sort of spins a little car in front of his eyes, and this lasts for about half an hour, and we leave him alone. We let him do it because it does rejuvenate him and bring him back to himself. Even at school he has some times where he tunes out and does some self-stimulatory activity, which normally I don't encourage, but it seems to really help him, so I allow some of it that is socially appropriate. (Interview #4)

Finally, in some of the interviews, additional medical concerns that impacted upon sleep were expressed. The most common of these related to feeding or gastroesophageal reflux. One child experienced a number of surgeries related to feeding issues; another was primarily medically managed.

He had reflux, so he would drink 2 ounces or whatever and it would come up. He would fall asleep and he would be hungry. It was just an ongoing thing every two hours. (Interview #1)

5.2.2 Child Sleep Related Needs

The interviews attempted to address the sleep related needs of each child. A consistent bedtime routine was enquired about and described for each child, and in many instances was an integral part of the child's preparation for bed. The routines described included typical pre-bedtime activities such as bath time, pajama time,

reading, snacks, and reading/snuggling time. Many parents described difficulties in getting their child to settle for sleep despite the presence of routine. This was generally felt to be related to difficulties in self-regulation or self-soothing, as distinguished from behavioural bedtime resistance.

C. is one of those children that get all wound up, takes a long time to settle down and just like any other thing...he can run himself until he is crying, cause he's tired, he wants to go to bed but he has to be told and so when I put him to bed, he probably is moving around and everything else, but he is in his own way settling down. So, I waited for him for the hour that he quits moving around, I put him to bed then, he'd still need that time to settle down anyway. So, even though I feel guilty, I've just always put him to bed at bedtime and just let him settle down. (Interview #9)

Most of the children had difficulties with behavioural state organization and self-regulation, which was particularly evident prior to bed. Parents therefore provided a number of external "state regulators" for their children. A number of the parents felt that their children were soothed by being rocked or stroked before bed even as the children were older, and felt that this helped them organize their movements and settle their thoughts.

I was still rocking him at a point just to get him to sleep...I would lie there, he got too heavy, and just tell stories or sing songs and he would fall asleep...It was really so hard, and I did it for I don't know how long, and then as he got older, my husband started doing it... (Interview #1)

The presence of environmental white noise, such as a fan, also seemed to help in calming children.

I will still put the fan...if you didn't, he would tell us to put the fan on because he got used to it...so I found like if I didn't have it on, he wouldn't really [sleep better], and now he does. (Interview #1)

Some of the children were also soothed by a process of bundling which could include heavy blankets, tucking in, or arranging pillows. This was also felt to provide some external pressure or reminder to physically settle their body and their movements. A similar effect was provided by firm massage following a bath for another child.

...later as he got older, we had pillows all in one corner for him...we have his little corner...his little space (Interview #1)

He needed to be bundled for quite a long time...We have these sort of rough, massaging type of gloves that we rub him down with, and he really likes that with some gel. Before this, he gets a bath with a calming lavender bath from the States...Then we do the rub down with the gloves, and he really likes that. Then, we go into the rocking chair and we rock him for about 15-20 minutes. Then, we go up to his room where we read him a story, and then he knows he has to lie down or play quietly. (Interview #4)

For all of the children, parental presence at night was important. The limits set upon the amount of this presence varied with each parent, but the demand for their

presence was universal. This was also felt to be a form of external state regulation, but also seemed to be related to issues of insecure attachment.

He will still come down in our room. But as long as he knew you were there, he would be fine, and otherwise, he would either ... We did know at the time, you know then, but we figured, well, he'll get older and then it'll get better, but it got better to a point, but we still have trouble getting him to sleep (Interview #1)

All parents agreed that the overall need for nighttime sleep in their alcohol affected child appeared to be less than in their other children. These children generally did not nap during the day. However, their parents frequently commented upon daytime fatigue. If they did nap, their nighttime sleep seemed to be adversely affected. Most parents preferred to give up the daytime sleep in favour of trying to increase their child's sleep at night.

It depends if he has a nap during the day, he has a hard time going to sleep at night ... He will go to bed, before when he would have naps at daycare, he would go to bed around 8:00 or 9:00, but he would not fall asleep until, like, he would still be up when I would go to bed at around 11:00, and then he would wake up early in the morning. He would be up before I get up. He will be up when my husband is going to work ... and my husband is up by 6:00 and a lot of times T is up when he is up... I have noticed that when I go to pick up my husband, T will have a little catnap in the van at around 4:00 ...I find him on occasion sleeping at the table, eating supper...(Interview #6)

5.2.3 Parent Impressions of Sleep Behaviour in Alcohol-Affected Children

All of the parents in the study were foster parents, and had received parenting support through community agencies dealing specifically with alcohol affected children. All of the parents were also experienced foster parents of special needs children, many of whom were alcohol affected, and also based their impressions upon their own previous experiences. Most of them had developed a structured approach to the care of their children based on their experience. Some parents had attended educational seminars that described behaviours and approaches to managing them. Most parents anticipated hyperactive and impulsive daytime behaviours, and anticipated carry-over of these behaviours at nighttime.

*I go to meetings, or have, I haven't lately, but different people with fetal alcohol kids...tell me these horror stories and...it's not sleeping that's going to give him better behaviour, I think I'd rather him sleep and have to deal with a little bit of hyperactivity, you know, because everybody needs their sleep
(Interview #3)*

*I'm told some of these kids are awake sometimes for hours you know
...they just figured that was normal for what he had (Interview #1)*

Many of the impressions parents shared about children with FAS were consistent with literature-based observations of this group of children. They noted hyperactive behaviour, a variety of sensory behaviours such as licking or rubbing, impulsivity, lack of judgment, and some self-stimulatory behaviour. While most of the time, these

behaviours were based in their experience of their child, occasionally their observations seemed “magically” based:

Full moon, time of the month, nothing helps. We have noticed that pattern. He just gets extremely rowdy, rangy; you can't really do anything with him ... pain didn't affect him (Interview #3)

None of the parents commented on any abnormalities of sleep in the children chosen to be controls for this study, despite in some cases, apparent restlessness or wakefulness noted using the quantitative measures. Patterns of sleep seen in their alcohol-affected children as abnormal or requiring treatment, were not identified as abnormal to the same degree in their other children.

...to be quite honest, my son, R, can be just as bad ... I shouldn't use that word, but I'm going to, his behaviour can be just as bad as S's and there is no fetal alcohol there. I just think he's [S] been dealt a bad hand, he's got the behaviour problems but don't allow that to not let him learn things himself. (Interview #3)

M will wake up, so I have to get up. But he'll get up and come in and just sit there and stare out the window, like, I don't have to worry about him. He's very good that way, which is really nice. (Interview #1)

Developmentally normal sleep patterns in preschool age groups, such as night terrors, were viewed as abnormal behaviours in the alcohol affected children, related to alcohol effects. This perception was reinforced by professionals in the community.

...he would wake up with the shakes. Yes, that's it. That's right...he used to wake up crying, and we would go up there, and it was like he doesn't even know that you are there...I know my son, A, has had a couple of those, where he has woken up crying and shaking, and you have gone in there to calm him down...A just goes through those once in a blue moon...but T used to get several. I complained to someone about it, or not complained but asked because I was scared because we couldn't figure out what it was, and he would wake up and he would just be shaking and just trembling. I remember that's when my mom was here, I think that's when it happened...T slept with her down here, and he woke up with one, that's when we started, and she's a nurse, and she's the one that said that's something that's not normal.

(Interview #7)

Perceptions of abnormality persisted, despite normal behaviours. Thus, nightmares and sleep talking, other developmentally normal sleep behaviours in preschool children, were again identified as abnormal sleep behaviours in the alcohol-affected children.

5.2.4 Parent Responses to Sleep Disturbance

Parent responses to sleep disturbance in the alcohol-affected children were varied and often reactive. Parents spent considerable energy trying to reshape and teach

behaviour, but often found themselves reacting to nighttime activity or restlessness before bed.

We tried having his other toys in the bedroom, but he would just play too much, you know, and he would not settle down, so there are just his stuffed toys in there, unless he sneaks something in. But other than that, no, we had to remove everything that was playable, because he would play instead of going to sleep. (Interview #3)

Parents tried to soothe the developmental parasomnias experienced by many of these children.

All I know is what we did, we just held him tight and tried to soothe him back to sleep and then he'd be okay. But, I remember it was pretty scary, because he would just wake up and just shake and cry, and it was like we were not even there. (Interview #6)

Most of the sleep disturbances continued for months to years and thus took a toll on parental energy levels and, in some instances, family relationships. Parents generally took an initially philosophical attitude to the sleep deprivation they experienced themselves. Many however, expressed a sense of frustration at times, at the demands placed upon their energy and family functioning.

I think there must have been a lot of tension, like with everybody too, because you get on edge when you don't get that sleep...My husband worked so it was okay. He was away from it all day, so it didn't really matter. He didn't mind it that way. (Interview #1)

We have a lot of moments here, where you know, you just want to throw your hands up and say, what am I doing...And you know, to me, I guess it's when you have been living it for so long, that this is the way things happen, and if you have difficulties, or whatever it's just the way it is...I think as the years go on, it gets easier. (Interview #6)

Some parents also felt that the time spent soothing their alcohol affected child was disproportionate to that spent with their own children, and expressed regret over the time perceived as taken from their other family relationships.

Well, our kids are probably more on a stricter schedule, they probably don't get to do a lot because we know T can't handle it...They don't get our full attention that they could have had, now instead of dividing it between three children, we have to divide it between five...It's just that I think that a lot of one-to-one with mom and dad, like we can't. (Interview #6)

The effect of the child's increased energy level and resultant sleep deprivation for the parents was described as having pervasive effects upon the functioning of the household.

Sometimes when he gets up, you know what kind of day it's going to be, is it a C day or a my day? (Interview #1)

Each parent struggled in their own way to create a sense of normalcy for their child while acknowledging the challenges that each child presented.

If you start treating them like they have a problem, they will have it.

(Interview #3)

A sense of recognition for their efforts was important to many families, though often not acknowledged.

We have put in a lot of time, a lot of work with him and just, I mean it's all worth it, but you know darn well you're not going to get appreciated for it even when he's older. (Interview #1)

5.2.5. Parents' Advice to Others

Parents were generally pleased to have the opportunity to offer their own advice to others based on their experiences. Most of the advice was solid and based in common sense, such as advice to have a daily routine or schedule, maintain a soothing bedtime ritual, maintain consistency between parents, and provide stability for the children. Some parents felt a "cry it out" approach would be the most efficient; others were quite physically responsive. All the parents felt that community based supports, such as Interagency FAS or therapy services, were valuable in providing information and practical support around sleep issues as well as general parenting issues.

Anita to me did the most from the Interagency FAS Program. Without her, I don't know what I would have done...She got all the information. It was just unbelievable...and made me feel like I wasn't doing something wrong, it wasn't me (Interview #1)

Physicians also provided important information to families about behaviour and management. Accessibility and a sense of support was extremely important to families.

...she told me lots of things to do and see and read in the library and everything...people don't realize how hard it is with these kids and when you do get any spare time, you just either want to sleep or just catch up on what you have lost and you just can't get out all the time or you don't want to because you feel it's a waste, but you have to, I know, but just talking to her like that for a few minutes helps even. You know, someone else understands.
(Interview #1)

Families commented on maintaining a sense of humour, and often relied upon other friends or family members to help maintain it.

I would get so uptight and I would tell everybody; if I didn't cry, I knew I had a good day. Cause every night I was crying, just because I would be tired out and I felt better, till it got to be a joke. Same with the puking up, "I have a new scent, it was 'Pukation" on me, perfume". (Interview #1)

The use of complementary and alternative medicine was discussed and recommended by two families. One family tried a herbal remedy to address hyperactive behaviour and felt it helped manage pre-bedtime behaviour to a degree. They also felt that some of the behaviour was innate to the child and that "nothing helps."

He just gets extremely rowdy, rangy; you can't really do anything with him...I just try and restrict him, like his activities, not get him too wound

up...[I give him] the same dose all the time. I have noticed there have been a couple of times where I have quit them and I have noticed, going off of them, I notice it more than going on them, if that makes sense” (Interview #3)

The other family coupled an aromatherapy with a soothing pre-bedtime routine as recommended by their occupational therapist, and felt that this was a helpful routine for the child (see section 5.2.2).

The establishment of a consistent routine, not just at bedtime, but throughout the day, was recommended by nearly all the families, and all of them commented upon how they used routine in their own parenting. Routine was felt to be especially important to alcohol-affected children to facilitate their adjustment and learning, as well as to provide external state stability and consistency for them.

The routine is very important, and you can't break it, no matter where you go, even if you go out, you know, you need to make sure you have your supplies with you, like whether it is rubbing down a child, bundling a child, singing songs, keep that routine the same, no matter what. If another person needs to put this child to bed, they need to be aware of the routine, and they need to be able to do it...it's very important that the routine does get followed and also that you need to set rules about staying in bed even when a child is awake, because a child needs to be safe. Even in a child proof house, there is still stuff that a child can do that aren't safe when an adult isn't around it, so there needs to be very firm rules around sleep (Interview #4)

Alcohol babies need routine...the younger you get them the better it is, because they might not have remembered those experiences after 2-3 months...but routine...they're scared, but the only thing that is going to give them reassurance is to make sure that everything is safe day after day. So it might sound strict, to put them down there, but it's going to help them in the long run. (Interview #9)

All the families felt that it was important to feel supported, and to arrange break time for themselves and their families from the demands of childcare. A supportive partner was important to all of the families. Many of them commented on the physical relief given by one partner towards another, or even the emotional relief of an easy-going temperament. Formal respite support from other family or from community agencies provides balance and an opportunity to recharge caregiver batteries.

...the thing is, I know my limit. I know when I do need to farm someone out of the house...You do need to take time for yourself. Like, when your husband gets home, you know, take an hour and read that book. You need time away from children. That helps you a lot, just to, you know, recoup and refocus. You got to look at the good things about the whole thing. And, I find the good things usually do outweigh the things that aren't so good. (Interview #4)

5.3 Conceptual Framework of Sleep Disturbance in Alcohol-Affected Children

The qualitative themes that emerged from the interviews support a multifactorial conceptual framework of sleep disturbance (See Figure 5.1). The behaviours observed in these children by their families are consistent with the quantitative data. Alcohol-affected children are well documented to have difficulty with state regulation and self-organization. As a result, they have difficulty settling themselves at bedtime, and are often restless beyond their bedtime. Some children have learned to utilize self-soothing behaviours such as rocking; most children rely upon external regulators governed by a variety of parental techniques and environmental modifications.

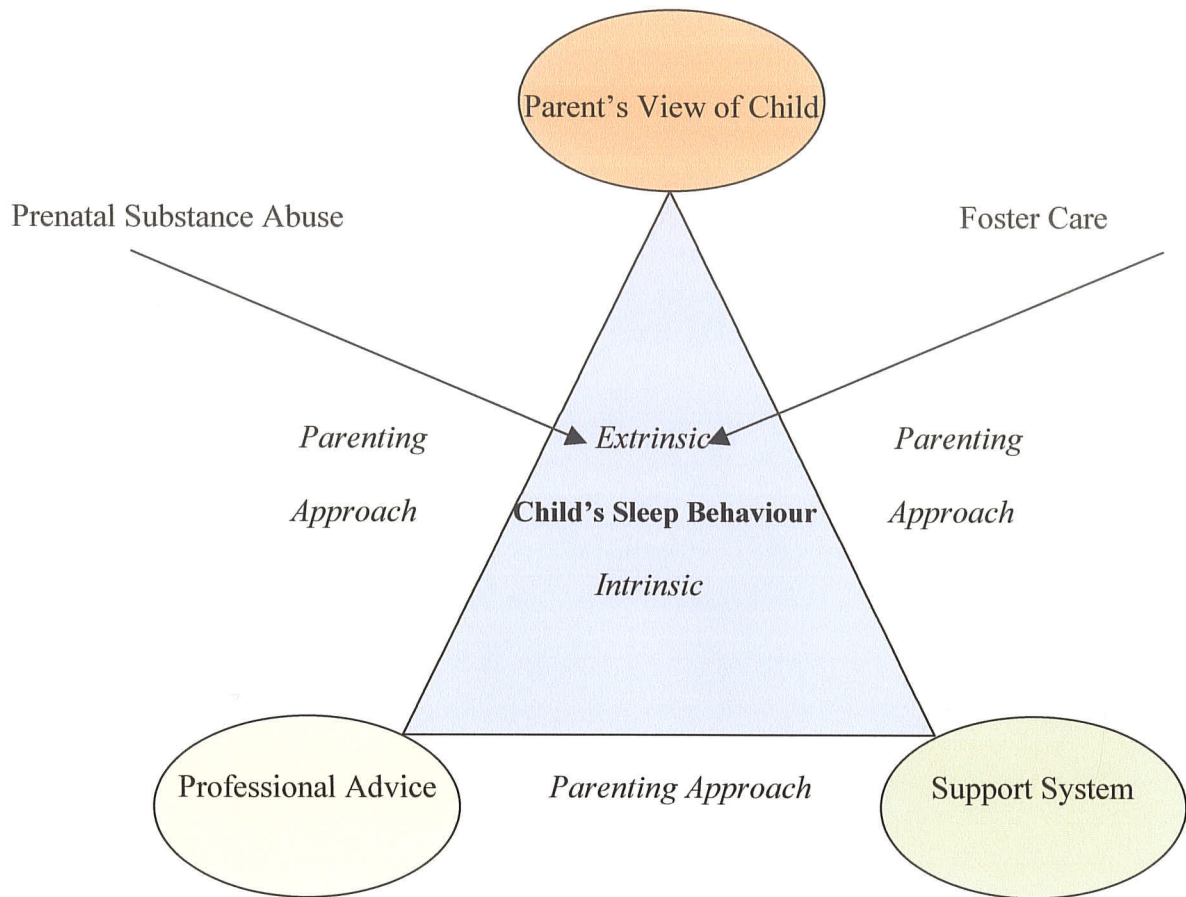
The children's parents react to the sleep disturbance in a variety of ways, including immediate responsivity, as well as separation. They seek advice and support from their own family, the community, and the professionals involved with their children. Each of these external regulators provides a feedback mechanism for parents to reshape their own behaviour and approach. Previous experience with other children also provides a basis for interpretation of sleep behaviour and effective responses.

While this study attempted to control for instability in placement, none of the children were living in their biological homes. The average number of placements of the children participating in this study was three, but one child had experienced eight previous placements (none within the preceding two years). Most of the families had other non-biological children living in the home. Previous work has explored the

negative effects of foster care on the development of attachment behaviour in infants (111). Other work supports a physiological regulatory effect of intimate parent-child interaction in infancy (112;113). Sleep disorders have been shown to be highly correlated with insecurely attached parenting (114). The children in this study were not psychologically assessed with regards to attachment security or ability to form attachment relationships. Nonetheless, given the disruption in their care experiences as described by the number of placements they experienced, it would be reasonable to examine contextual contributing factors to their sleep disturbance.

The interviews in the qualitative component of this study provided contextual data for the quantitative measurements taken in the first part of the study. They describe the caregiving environment experienced by the children, and allow inferences to be drawn regarding the contributing factors to sleep disturbance and effects on family. It was clear throughout the interviews that each foster parent was committed to the care of each of their children, and struggled to provide loving responses to challenging behaviours. Each of the foster parents who participated in these interviews expressed long-term commitments to their child. They also expressed a desire to provide support and experiential information to other parents who may be experiencing similar challenges in caring for alcohol affected children. Each parent expressed a desire to participate in the study in order to increase the general knowledge about alcohol-affected children and ways of assisting these children cope with day-to-day activities.

Figure 5.1: Conceptual Framework for Sleep Disruption in Alcohol Affected Children



CHAPTER 6 – DISCUSSION

This study is the first to describe the sleep characteristics of alcohol-affected children. This study has utilized both quantitative and qualitative methods to describe these sleep characteristics in this complex population, and this combination is a major strength of this work. This study was also well supported in the community by both foster parents and their agencies who recognized the need to understand the sleep patterns of these children in order to provide optimum treatment and support to both the child and their family.

While sleep disturbance in alcohol-affected children is generally commented upon in literature describing their behavioural characteristics, there is no published work attempting to describe the specific parameters of this sleep disturbance. A number of factors may contribute to the lack of literature in this area, including difficulties in separating the environmental effects on sleep patterns from biological effects, controlling for individual substances in the face of potential multisubstance exposure, and difficulties in quantifying exposures. In addition, there are a number of practical considerations in studying alcohol-exposed children and their families. Many children prenatally exposed to alcohol are in foster care, often coming from unstable home situations, and experiencing a variety of parenting approaches to their care. At the Clinic for Drug and Alcohol Exposed Children in Winnipeg, 71% of the children assessed in the clinic live outside their biological home; 62% are in foster care (21). Literature on attachment and sleep in infants and young children seeks to describe

sleep a marker of psychological adaptation. Thus, sleep difficulties reflect dysfunctional states of socio-emotional as well as neurobiological regulation and organization (112;114;115).

This study was limited by a number of methodological and pragmatic factors, which are also, paradoxically, part of its strengths. The identification of same-household, healthy controls for each study attempted to control for the effects of different parental approaches to bedtime management. This also proved to be a significant limiting factor, as it severely limited numbers of children and families available for study. Most of the children were in foster placement, and many households provided foster care once their own children were grown and therefore not available for study, or fostered multiple affected children.

We attempted to control for stability in placement by requiring a period of at least one year in the current household. This further limited numbers, and it is dismaying to note the number of young children with histories of multiple placements. Even in this small study, one of the nine children had been placed eight times, but met eligibility criteria through recent stability in placement. The original intent was to obtain enough children in each diagnostic group (FAS, Partial FAS, ARNDD) to be able to perform relevant data subanalyses by diagnosis. However, given the final sample size, children were analyzed in their larger groups, alcohol-affected by non-alcohol exposed controls. Future study would benefit from the creation of a sleep database

of alcohol-affected children in each diagnostic category. A separate database of developmentally healthy children could be kept for ongoing cohort analysis.

The use of actigraphy to study sleep parameters in this group was chosen for its relative ease of use, lack of invasiveness, good correlation with polysomnographic data, and relative inexpense. The validity of actigraphy, however, has not been established in all clinical groups. Furthermore, it has been recently noted that actigraphy alone should not be used for the diagnosis of sleep disorders in groups with motor disorders or hyperkinetic behaviour in sleep (116). Given the underlying established neurological dysfunction of these children, and the variability in presentation of alcohol related diagnoses, gold standard polysomnography should be specifically utilized to identify an electrographic baseline and description of sleep architecture in alcohol-affected children. To date, this type of clinical study has not been published. A polysomnographic baseline would also provide data for the establishment of actigraphic reliability in this population of children, for whom an ambulatory method of sleep study would be practical. Finally, some authors continue to challenge the assumptions made in Sadeh's initial studies, particularly related to the sensitivity of actigraphy in the identification of specific sleep parameters (117). Thus these data could also provide confirmatory support for Sadeh's assumptions.

The comorbidity of disorders of motor and attentional controls in alcohol-affected children is a significant issue that will need to be addressed in future work. These disorders are frequently not diagnosed formally until school age, and would therefore

have been missed in some of the children included in this study. Children with Attention-Deficit/Hyperactivity Disorder (ADHD) have been studied using actigraphy, and sleep questionnaires (104;118-120). Future work would require larger numbers of children for appropriate comparisons of clinical groups of children with an alcohol related diagnosis (FAS, Partial FAS, and ARNDD), children with dual diagnoses (alcohol related and ADHD), and those with ADHD alone.

The prevalence of sleep problems such as night awakenings decreases through childhood and adolescence, related to central nervous system maturation (121). Recognizing the permanent effects of alcohol on the brain suggests a long term deviance in neurological maturation that could have long term effects on sleep. These abnormal effects would be closely linked to the developmental/maturational processes of normal sleep. Thus, the sleep of a large cohort of alcohol-affected children studied longitudinally at different ages would provide important information about sleep disturbance as well as about the long term neurological sequelae of prenatal alcohol exposure and developmental outcome.

The demographic and behavioural data collected in this study are consistent with demographic data in previous behavioral studies of alcohol affected children (122). Children prenatally exposed to alcohol and substances of abuse are more likely to experience foster placements, and often multiple placements (25;122). Whaley and colleagues' study of the adaptive functioning of children exposed to alcohol compared with a non-exposed group supports a negative impact of multiple

placements on socialization behaviour. Furthermore, alcohol exposed children showed more rapid declines in socialization behaviour with age (122). Longitudinal study of psychopathological outcomes in alcohol affected children has supported high rates of social disruption and persistent psychopathology including sleep disorder with age (6;33). The present study is the first to provide specific data describing the sleep disturbance seen, and describes the presence of externalizing behaviour with daytime fatigue in these children. Further correlative study with larger groups will be required to understand the relationships between these data.

The long-term development of alcohol-affected children in foster care has been studied (28;123). Exposed children show a higher incidence of behaviour problems compared with family foster care peers (123). They continue to demonstrate lower cognitive scores with specific areas of learning disability. Finally, it is suggested that even with adequate foster care arrangements, the substance exposure itself is still an independent risk factor for further developmental problems (28). Thus, there is face validity for the observation of specific and biological differences in sleep patterns of alcohol-exposed children that may be impacted by, but not accounted for by environment alone.

The parent-rated behavioural and emotional disturbances in children prenatally exposed to alcohol has been well documented in the literature (32;124;125). These reports describe hyperactive, often aggressive, and externalizing behaviours in alcohol-exposed children. These behaviours are generally felt to be related to

pathological correlates in self-regulatory and inhibitory brain areas. In otherwise healthy infants, low levels of self-regulatory abilities have been correlated with poorer social and cognitive development (71). The relationship between sleep problems and daytime behaviour problems in young children has also been described (126). The presence of sleep disturbance in alcohol-affected children would therefore likely have both an aggravating as well as potentially contributive role in the behavioural disturbances seen in these children.

The purpose of the qualitative interviews in this study was to identify family understandings of the sleep patterns of their alcohol affected child, and describe the impact on the family of their sleep disorder. Many of the families were eager to participate, and their data added richness and support to the quantitative data collected. Unfortunately, not all of the families were available to be interviewed, which may have been related to the foster status of the parents, the interviews being audio taped, or a simple reluctance to participate.

There is only one published qualitative study in the literature seeking to describe the experiences of foster parents living with an alcohol affected child (127). In this study, foster parents described a range of cognitive and behavioural effects of alcohol in their child, as well as their own difficulties in coping with the care of that child. It was both difficult and helpful to them to describe their child as not “normal” in order to match their expectations to the day to day struggles with their child’s behaviour. They described conflicting feelings of love for their child with fear for their future. In

the present study, foster parents of these children express a similar range of conflicting emotions ranging from love and pride, to frustration and fatigue. Parents of these children live with significant behavioural challenges on a daily, and nightly, basis. They look to their family, friends, community, and professionals for support and advice for specific problems. Sleep disruption is widely acknowledged, but poorly understood, by the professionals who provide guidance to families. No specific treatments are supported in the literature. In the community, a range of approaches ranging from sensory to herbal to behavioural are described, but none have been critically analyzed.

The purpose of the qualitative portion of this study was to describe and acknowledge the experiences of families caring for their alcohol affected child with sleep disturbance. Their experiences underscore the need to medically understand this disturbance in order to provide appropriate treatment for these children. The goals of treatment should reflect the multifactorial contributors to sleep disturbance including the child's biology, their family context, and community supports. Future qualitative study of both affected children and their families will facilitate understanding of the varied influences on behaviour and coping with sleep disorder.

CHAPTER 7 – SUMMARY AND DIRECTIONS FOR FUTURE RESEARCH

The gold standard for the assessment of sleep processes is polysomnography. To date, there are no published polysomnographic studies of alcohol affected children. The present study should provide support for the further study of the sleep characteristics of alcohol affected children using complete and gold-standard laboratory methods of sleep evaluation. This work should be prospective and longitudinal, as literature supporting developmental patterns of sleep with age is well documented. Furthermore, work should continue to quantitatively evaluate the potential dose response relationship of alcohol, and the environmental factors that contribute to its toxicity.

Understanding sleep behaviours of alcohol affected children will require a physiologic understanding of neuronal mechanisms affected by alcohol, as well as the role of these mechanisms in sleep processes. Thus, biochemical data regarding neurotransmitters and hormonal effects will provide additional understanding in the mechanisms of sleep disturbance in these children. Work using both animal models of fetal alcohol syndrome, as well as clinical correlates will be fundamental in developing an understanding of the pathology of alcohol toxicity. Understanding these processes will have implications for treatment of specific manifestations of alcohol related disorders including sleep disorder.

Sleep disorders in alcohol affected children are a commonly described but poorly understood process. This study has described specific sleep related behaviours including fragmented and restless sleep in alcohol-affected children. Their total sleep requirement is not significantly different from otherwise healthy children, thus supporting qualitative parental observations of increased daytime fatigue. The behavioural relationships between disrupted sleep and hyperkinetic disorders deserves further study in order to provide optimum treatment recommendations. The sleep disturbance in alcohol-affected children must be formally studied using gold standard techniques and larger cohorts of children. The contextual factors contributing to sleep disturbance and family coping must be understood in an ecological fashion in order to provide appropriate treatment to these children and support to the families who care for them.

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Sleep Disorders in Children with Fetal Alcohol Syndrome

Dr. Ana C. Hanlon-Dearman

*Child Development Clinic
Children's Hospital of Winnipeg
Children's Hospital Research Foundation*

This study is part of Masters thesis work in the Department of Community Health Sciences and is funded by the Children's Hospital Research Foundation.

Thesis supervisors are: Dr. Terri Benoit, Dr. Hans Pasterkamp, Dr. Jane Evans

What is this study about?

Children with FAS/FAE have a number of sensory and behavioral issues. From talking with families, we know that sleep is often a difficult issue; however, to date it has not been studied in these children.

Our objectives for this study are:

1. To describe the prevalence of sleep disorders in children with FAS, partial FAS, and ARND
2. To describe the types of sleep disorders through the use of questionnaire, sleep log, and actigraphy

Inclusion criteria

- ◆ Ages 1-8 years
- ◆ Genetic diagnosis: FAS, partial FAS, ARND
- ◆ Medically stable (no medications, no chronic disease)
- ◆ Stable placement (>1 year)
- ◆ Agreeable and available for actigraphy
- ◆ Controls available (healthy foster siblings, similar age and gender)

How many children do we need?

10 FAS, 10 partial FAS, 10 ARND, 30 controls

How long will the study take?

We hope to have all the data collected in 5 months

Follow-up

This is a descriptive study. Children identified with sleep disorders will be appropriately referred. We hope to be able to develop further work in this area on the basis of this study.

CONTACT: Dr. Ana C. Hanlon-Dearman, Child Development Clinic 787-2423

Appendix B: Consent Form - Quantitative Study
SLEEP DISORDERS IN CHILDREN WITH FETAL ALCOHOL SYNDROME

PARTICIPANT INFORMATION AND CONSENT FORM

Title of Study: SLEEP DISORDERS IN CHILDREN WITH FETAL ALCOHOL SYNDROME

You are being asked to participate in a human research study. Please take your time to review this consent form and discuss any questions that you may have with the study staff. You may take your time to make your decision about participating in this study and you may discuss it with your regular doctor, family and friends before you make your decision. This consent form may contain words that you do not understand. Please ask the study doctor to explain any words or information that you do not clearly understand.

Purpose of the Study

This study is being conducted to investigate the prevalence of sleep disorders among children with a history of prenatal exposure to alcohol and to describe the clinical nature of those disorders. Children who participate in this study will be compared with children who are not alcohol affected. All children who are being studied are between 1 to 8 years of age. A total of 60 children will participate in this study.

We know that some children who have been prenatally exposed to alcohol may display a group of physical and behavioral features known as Fetal Alcohol Syndrome, partial Fetal Alcohol Syndrome, or Alcohol Related Neurodevelopmental Defects. Behavioral features associated with the prenatal effects of alcohol include learning disorders, hyperactivity, attention deficit disorders, and emotional disorders. Abnormal sleep patterns in association with alcohol effects have been frequently noted in the literature but they have not specifically described.

Study Procedure

In this study, we will be studying sleep in a number of ways – indirectly through a sleep questionnaire and a sleep diary or sleep log, and more directly through the use of a motion detector known as an actigraph .

Sleep Questionnaire: You will be asked to complete a questionnaire that will help us describe the sleep patterns of your child. We will ask you to return this questionnaire to us within one week in a postage paid envelope.

Sleep log and Actigraphy: Following your completion of the questionnaire, you will meet with the study doctor who will review the questions with you. Your child will then be examined by the doctor who will measure their height and weight, examine their ears, nose and throat, and listen to their chest with a stethoscope. You will then be asked to keep a sleep log on your child. This will ask you to note the number of times your child sleeps in a 24 hour day, for how long, and any behaviors you notice during and around sleep. We will ask you to keep this diary for 1 week. During this time, we will also ask your child to wear a device known as an actigraph on their ankle. An actigraph is a small device which looks much like a wristwatch. Its purpose is to record your child's movements, which helps us to describe their sleep.

We will explain the results of the sleep study with you and your child. If the study is abnormal, we will discuss different behavioural approaches to managing your child's sleep. Sleep medication is not part of this study and will not be offered. However, if it appears that medication would be of

benefit to your child, we will discuss this with you, and with your permission we will share this information with your doctor.

Benefits

By participating in this study you will provide valuable information to the study doctors about the types and occurrence of sleep disorders in children who have been prenatally affected by alcohol. If your child's sleep is felt to be disordered, s/he may benefit from follow-up suggestions to improve their sleep. We hope that by describing sleep in different populations of children, such as children with FAS, we may better understand the effects of alcohol exposure in children, and eventually be able to treat children more effectively.

Costs/reimbursements

All clinic fees, professional fees, and diagnostic tests (actigraphy, questionnaires and diaries) performed as part of this study are provided at no cost to you. You will be reimbursed for expenses related to taking part in this study, such as parking at Children's Hospital for clinic appointments.

Confidentiality

Information gathered in this research may be published or presented in public forums; however, your name will not be used or revealed. Despite efforts to keep your personal information confidential, absolute confidentiality cannot be guaranteed. Your personal information may be disclosed if required by law. The University of Manitoba Faculty of Medicine Research Ethics Board may inspect and/or copy your research records for quality assurance and data analysis.

Voluntary participation / withdrawal from the study

Your decision to take part in this study is entirely voluntary. You may refuse to participate or you may withdraw from the study at any time. Your decision to not participate or to withdraw from the study will not affect your medical care. If your study doctor feels that it is in your best interest to withdraw you from the study, your study doctor will remove you without your consent.

Questions

You are free to ask any questions that you may have about the study and your rights as a research participant. If any questions come up during or after the study, contact the study doctor: Dr. Ana Hanlon-Dearman at 787-2423.

For questions about your rights as a research participant, you may contact The University of Manitoba Faculty of Medicine Research Ethics Board at (204) 789-3389.

Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

I agree to participate and enroll _____ in this study on sleep in alcohol affected children.

Date _____

Signature of parent/guardian _____

Witness _____

PARTICIPANT INFORMATION AND CONSENT FORM

Study Title: Experiences of Families Dealing with Sleep Disorders in their Alcohol-Affected Children

Researcher: Dr. Ana C. Hanlon-Dearman

Thesis Advisor, Dr. Jane Evans

Thesis Committee: Dr. Terri Benoit
Dr. Sharon Bruce
Dr. Hans Pasterkamp

You are being asked to participate in a research study conducted as part of a Masters Thesis on Sleep Disorders in Alcohol-Affected Children.

Please take your time to review this consent form and discuss any questions that you may have with the researcher. You may take your time to make your decision about participating in this study and you may discuss it with your regular doctor, family and friends before you make your decision. This consent form may contain words that you do not understand. Please ask the researcher to explain any words or information that you do not clearly understand.

Purpose of the Study

This research is part of a larger research project, "Sleep Disorders in Children with Fetal Alcohol Syndrome", in which you have already generously participated. I am asking you today to participate in a tape-recorded interview regarding your child's sleep pattern and the impact of this on your family.

Children who have been prenatally affected by alcohol may have sleep patterns that impact the functioning of the whole family. The purpose of this interview is to understand what your experience as a family has been with your child in dealing with these sleep patterns. Your participation is valuable and much appreciated.

Study Procedure

This study consists of a single tape-recorded narrative interview, conducted by the researcher. The interview will be 1-2 hours in length, held at your convenience at a mutually agreeable location. The interview will consist of open-ended questions which will explore your understanding of your child's sleep patterns, how you have tried to help your child, and what has helped the most. A brief, non-recorded follow-up telephone call may be used, if needed, to clarify any aspects of the original interview. The tape-recorded interview will be transcribed following the interview for analysis.

Benefits

There may be no direct benefits to you by participating in this interview; however, you will provide valuable information about your experience in dealing with an alcohol-affected child and their patterns of sleep. This information will be used to enrich the information gained in the first part of the study.

Costs/reimbursements

There is no reimbursement for this portion of the study.

Confidentiality

Information gathered in this research may be published or presented; however, your name will not be used or revealed. All tape recordings will be stored in a locked and secure place until research is complete, and then they will be destroyed. Despite efforts to keep your personal information confidential, absolute confidentiality cannot be guaranteed. Your personal information may be disclosed if required by law. The University of Manitoba Faculty of Medicine Research Ethics Board may inspect and/or copy your research records for quality assurance.

Voluntary participation / withdrawal from the study

Your decision to take part in this study is entirely voluntary. You may refuse to participate or you may withdraw from the study at any time. You may refuse to answer any questions you chose, and you may terminate the interview at any time. You are also free to ask any questions you may have about the interview or the interview process. Your decision to not participate or to withdraw from the study will not affect your medical care. If the researcher feels that it is in your best interest to withdraw you from the study, you will be withdrawn without your consent.

Questions

You are free to ask any questions that you may have about the study and your rights as a research participant. If any questions come up during or after the study, contact the researcher: Dr. Ana Hanlon-Dearman at 787-2423.

For questions about your rights as a research participant, you may contact The University of Manitoba Faculty of Medicine Research Ethics Board at (204) 789-3389.

Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

I, _____ (parent/guardian) agree to participate in this interview study on our family experience with the sleep of our alcohol-affected child.

Signature of parent/guardian _____

Date _____

Person explaining the Consent Form _____ (printed name)

_____ (signature)

Date _____

How to Take Care of the Actigraph

The actigraph is about the size of a sports watch. It is made to be as simple and as durable as possible. In the back, there is a 3 volt lithium battery. Inside the box itself is a motion detector and data recorder.

There are a few simple points to know in caring for this actigraph.

1. This actigraph is NOT waterproof. Please do not wear it in the bath or while washing.
2. The actigraph is about as strong as a sports watch. Please avoid dropping it onto hard surfaces, from great heights, or striking it into concrete walls or other hard surfaces when moving about.
3. You may lightly cover the actigraph while it is being worn.
4. Do not attempt to clean the actigraph. If it becomes dirty, please call me at 787-2423 for advice.
5. Do not attempt to open the back or change the battery. If you have any concerns, or if the back is opened accidentally, please call me at 787-2423.
6. When the actigraph is not being worn, please store it in a safe place, that is not accessible to the children.
7. Please return the actigraphs in the bubble wrap and padded envelope you have been given.

Thank you again for participating in this study.

If you have ANY questions about the care or use of this actigraph, please call me, Dr. Ana Hanlon-Dearman at the Child Development Clinic, 787-2423.

Pediatric Sleep Questionnaire

Introduction

Thank you for taking the time to read about this questionnaire.

My name is Dr. Ana Hanlon-Dearman. I am a pediatrician and a research fellow in the Child Development Clinic. I am interested in children's sleep habits and behaviors, and what we may be able to do to help your child sleep better. I am especially interested in studying sleep in children with developmental problems who may be having trouble sleeping.

Problems with sleep are common! 15-20% of all children visiting their pediatrician may have some problem related to their sleep. In children with developmental disabilities, that number may be as high as 80%. Furthermore, their sleep problems may be particularly difficult to manage.

We know that if a child has a good night's sleep, and feels rested during the day, that mood, concentration, and behavior may all be improved – certainly no different from any of us! We don't always know why we may not be getting restful sleep, or enough of it. A child who is awake and alert during the day performs better, and gets along better with everyone. That helps the whole family!

I appreciate your time and consideration in filling out this questionnaire. Your information will be valuable to this study!

Introductory Data

1. The questionnaire is completed by

- Biological parent
- Other biological relation
- Foster parent
- Legal guardian

2. If your child is in care, for how long has s/he been in the most recent placement?

- 1-6 monthes
- 7-12 monthes
- 13-23 monthes
- >2 years

3. Your child's age

- 12-17 monthes
- 18-23 monthes
- 2-3 years
- 4-5 years
- 6-8 years

4. Your child is

- Male
- Female

5. Does your child have any chronic illness?
Please describe

6. Is your child on any medication?
Please describe

Pediatric Sleep Questionnaire

For the following questions, please note the appropriate responses:

Never	<1 time per week
Occasionally	1-2 times per week
Sometimes	3-4 times per week
Frequently	5-6 times per week
Always	Every day, 7 days per week

In general

1. What is your main concern about your child's sleep?

- Difficulty falling asleep
- Difficulty staying asleep
- Sleepy during the day
- Snoring
- Talking in sleep
- Sleepwalking
- Other sleep behaviors (Please describe)

2. Have any members of your child's family had concerns about their own sleep?

Please describe

Daytime Sleep

- | | | | | | |
|--|-------|--------------|-------|------------|--------|
| 3. Does your child nap during the day? | Never | Occasionally | Often | Frequently | Always |
| How many times? | 0 | 1 | 2 | >2 | |
| How long does each nap last? | | | | | |
| <input type="checkbox"/> 0-10min | | | | | |
| <input type="checkbox"/> 10-20 | | | | | |
| <input type="checkbox"/> 20-30 | | | | | |
| <input type="checkbox"/> >30 | | | | | |
| 4. Does your child fall asleep during the day (unexpectedly or between naps) | Never | Occasionally | Often | Frequently | Always |
| 5. Does your child appear tired or complain of fatigue during the day? | Never | Occasionally | Often | Frequently | Always |

- | | | | | | |
|--|-----------------|--------------|-------|------------|--------|
| 6. Have others commented on your child's level of alertness or behaviors during the day? | Never
Always | Occasionally | Often | Frequently | |
| 7. Is your child hyperactive during the day? | Never | Occasionally | Often | Frequently | Always |

Nighttime Sleep

- | | | | | | |
|--|-------|--------------|-------|------------|--------|
| 8. Does your child have a regular bedtime routine (e.g. story, TV, bath, backrub, music, etc)? | Never | Occasionally | Often | Frequently | Always |
| 9. Does your child regularly resist bedtime? | Never | Occasionally | Often | Frequently | Always |

10. What time does your child usually go to bed?
 Weekdays _____
 Weekends _____

11. How long does it take for your child to fall asleep?
- <10min
 - 10-20min
 - 20-30min
 - 30-60min
 - >60min

12. Does your child use a comfort (transition) object (e.g. blanket or toy)?	Never	Occasionally	Often	Frequently	Always
--	-------	--------------	-------	------------	--------

13. Where does your child sleep at night?
- Own bed/crib
 - Parents bed
 - Siblings bed
 - Other

14. How many times does your child wake at night?	0	1	2	3	>3
---	---	---	---	---	----

15. What is the most common reason for your child to wake at night?

- | | | | | | |
|--------------------------|-------|--------------|-------|------------|--------|
| Hunger/Feeds | Never | Occasionally | Often | Frequently | Always |
| Toileting/Diaper changes | Never | Occasionally | Often | Frequently | Always |

Play (incl. Reading and TV)	Never	Occasionally	Often	Frequently	Always
Dreams	Never	Occasionally	Often	Frequently	Always
Fears	Never	Occasionally	Often	Frequently	Always
Own movements	Never	Occasionally	Often	Frequently	Always
Other					

16. Does your child move excessively in their sleep? Never Occasionally Often Frequently Always

17. Does your child show any of the following behaviors during sleep?

Walking	Never	Occasionally	Often	Frequently	Always
Talking	Never	Occasionally	Often	Frequently	Always
Crying	Never	Occasionally	Often	Frequently	Always
Headbanging	Never	Occasionally	Often	Frequently	Always
Hitting/Kicking	Never	Occasionally	Often	Frequently	Always
Picking/sniffing bedclothes	Never	Occasionally	Often	Frequently	Always
Other (describe)					

18. How do you as a parent/caregiver usually respond to your child's nighttime awakenings?

Let child fall back to sleep on their own	Never	Occasionally	Often	Frequently	Always
Attend to feeding/toileting	Never	Occasionally	Often	Frequently	Always
Keep child company (play, read, talk, etc)	Never	Occasionally	Often	Frequently	Always
Help child to go back to sleep (rub back, sing, etc)	Never	Occasionally	Often	Frequently	Always
Other (describe)					

19. How many hours does your child usually sleep at night (total all nighttime sleep periods)?

- 1-3 hours
- 4-6 hours
- 7-8 hours

- 9-10 hours
- 11-12 hours
- >12 hours

Sleep treatments

20. Has your child ever tried any medication to improve their sleep? (Please check all that apply)

- Prescribed medications
- Vitamins
- Herbal remedies
- Herbal teas
- Over-the-counter treatments
- Naturopathic treatments
- Holistic therapies
- Family remedies
- Melatonin
- Other

21. Has your child using any sleep related appliances?

- Oral appliances
- CPAP/BiPAP
- Braces
- Special Pillows
- Special Beds
- Other

22. What therapies have you found to be most effective?

Describe

23. Has your child received any counselling for sleep related problems?

Describe

24. Has your child had a sleep study in a sleep laboratory?

When

Where

Results

25. Other comments

Thank you for taking the time to complete this questionnaire. Your time and effort will help us to learn more about children's sleep habits and patterns, and different ways we may be of help to them.

Once we have received this questionnaire, you will be contacted by our clinic to arrange an appointment for you and your child. At this appointment we will review the next part of this study. We will also examine your child to make sure they are healthy to participate.

Again your time and effort are much appreciated!

If you have any questions regarding this or any part of the study, please contact the study doctor, Dr. Ana C. Hanlon-Dearman at 787-2423.

Thank you for your time and effort!

Appendix G: Guiding Questions for the Qualitative Interview

Tell me about your family.

How long has your child been with you?

Tell me about your child.

Tell me about how your child sleeps.

How did your child sleep as a baby?

Has their sleep changed over time?

Is their sleep similar/different than your other children's sleep?

Does your child nap during the day?

Does your child seem tired during the day?

Have others commented upon their level of alertness?

Can you relate your child's sleep and their behavior?

Amount of sleep? Quality of sleep?

Do you feel their health has been affected by their sleep patterns?

Do you feel your health/sleep has been affected by their sleep patterns?

Do you feel your parenting has been affected by their sleep? Your sleep?

What techniques/approaches have you tried to help your child sleep?

What approaches have been suggested to you to help your child sleep?

By physicians/health professionals?

By family?

By others?

What has worked? What hasn't?

What do you feel would best help your child?

What would help you cope with this sleep problem?

What advice would you offer to other parents in a similar situation?