Parent perceptions of the effect of ADHD child behavior on the family : the impact and coping strategies

by Julie Anne Bullard

A thesis submitted in partial fulfillment of the requirements for the degree of Doctor of Education
Montana State University

Abstract:
The purpose of this research was (1) to describe parental perceptions regarding the impact of attention deficit hyperactivity disorder (ADHD) child behavior on personal and family functioning and (2) to describe parental perceptions regarding strategies used to cope with the ADHD behavior and the stress related to it. Information was obtained from 14 parents in Southwestern Montana who had diagnosed ADHD children between the ages of 6 and 12. A qualitative methodology was used, including multiple in-depth interviews with three parents resulting in three case studies. Three focus groups involving 11 additional parents were also held in three communities. The individual case studies and three focus groups were each analyzed for overriding conceptual categories. The final step in data analysis was to examine the findings from both the focus groups and the case studies for the emergence of patterns and themes common to both. The overriding themes that were identified were: 1) The ADHD child's erratic behavior-the severity, the unpredictability, and the number of years of occurrence make this particularly stress producing for both the child and the family. 2) Altered relationships-marital, sibling, extended family, and casual relationships were all described as changing as a result of parenting an ADHD child. 3) Social isolation-parents described having fewer visitors to their home and curtailing activities away from the home due to their embarrassment regarding the child's behavior, disapproval from others, and the demands of parenting an ADHD child. 4) Difficulties with school-discussion from parents centered around two concerns, the teacher not following IEP's or Section 504 plans and the time and energy involved in supervising homework. 5) Emotional upheaval-intense feelings of frustration, embarrassment, worry, guilt, hopelessness, and exhaustion surfaced repeatedly in the interviews. 6) Medication quandary-parents described the continual struggle to find a therapeutic dose of medication and a competent doctor. They also expressed concern about the medications side effects. 7) Coping repertoire -parents described using a wide variety of both problem focused and emotion focused coping strategies. However, in spite of these they discussed parenting an ADHD child as being extremely stressful or "an unremitting struggle" which was identified as a megatheme of the study.

APPROVAL

Of a thesis submitted by

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This thesis has been read by each member of the thesis committee and has been found to be satisfactory regarding content, English usage, format, citations, bibliographic style, and consistency, and is ready for submission to the College of Graduate Studies.

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Date 11-25-96

ACKNOWLEDGEMENTS

There is a saying that "It takes a whole village to raise a child." I would like to expand upon this to say that neither raising a child nor completing a doctorate occurs in isolation. Instead it requires the support and encouragement of many others. So I would like to take this opportunity to say thank you to some of my "village".

I wish to express my gratitude to the participating ADHD parents for your openness in sharing your lives.

To Dr. Randy Hitz, my advisor and mentor, for your thought provoking critiques and discussions. To Dr. Walt Oldendorf for your on-site support and unfailing encouragement. To my other committee members, Dr. Duane Melling, Dr. Jim Hauwiller, Dr. Elizabeth Charron, and Dr. Bill Hiscock for providing suggestions and guidance.

A special thanks to my external readers, Dr. Eve Malo, Dr. Alison Boyer, and Dr. Julie Maloney for your time and thoughtful analysis.

To my children Danny, Lisa, Christopher, and Scott and my husband Tim for your patience, encouragement, and also for being the source of inspiration for this topic. To my parents Ed and Anne Henderson for your unfailing confidence and support. To my friends and colleagues who helped to pick up the loose ends so that I could continue going to school. Thanks to my friend Elizabeth Cox for being a confidante and providing hospitality through graduate school.

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ABSTRACT

The purpose of this research was (1) to describe parental perceptions regarding the impact of attention deficit hyperactivity disorder (ADHD) child behavior on personal and family functioning and (2) to describe parental perceptions regarding strategies used to cope with the ADHD behavior and the stress related to it. Information was obtained from 14 parents in Southwestern Montana who had diagnosed ADHD children between the ages of 6 and 12. A qualitative methodology was used, including multiple in-depth interviews with three parents resulting in three case studies. Three focus groups involving 11 additional parents were also held in three communities. The individual case studies and three focus groups were each analyzed for overriding conceptual categories. The final step in data analysis was to examine the findings from both the focus groups and the case studies for the emergence of patterns and themes common to both.

The overriding themes that were identified were: 1) The ADHD child's erratic behavior-the severity, the unpredictability, and the number of years of occurrence make this particularly stress producing for both the child and the family. 2) Altered relationships-marital, sibling, extended family, and casual relationships were all described as changing as a result of parenting an ADHD child. 3) Social isolation-parents described having fewer visitors to their home and curtailing activities away from the home due to their embarrassment regarding the child's behavior, disapproval from others, and the demands of parenting an ADHD child. 4) Difficulties with school-discussion from parents centered around two concerns, the teacher not following IEP's or Section 504 plans and the time and energy involved in supervising homework. 5) Emotional upheaval-intense feelings of frustration, embarrassment, worry, guilt, hopelessness, and exhaustion surfaced repeatedly in the interviews. 6) Medication quandary-parents described the continual struggle to find a therapeutic dose of medication and a competent doctor. They also expressed concern about the medications side effects. 7) Coping repertoire -parents described using a wide variety of both problem focused and emotion focused coping strategies. However, in spite of these they discussed parenting an ADHD child as being extremely stressful or "an unremitting struggle" which was identified as a megatheme of the study.

CHAPTER 1

INTRODUCTION AND LITERATURE REVIEW

Introduction

Attention deficit hyperactivity disorder (ADHD), characterized by a brain difference (Amen, Paldi, & Thisted, 1993; Zametkin et al., 1990) and specific behavioral symptoms (Linden, Zalenski & Newman, 1989), is considered one of the most frequent and globally debilitating of childhood disorders (Barkley, 1981; Trites, Dugas, Lynch, & Ferguson, 1979). ADHD children, their parents, schools, and society feel severe impacts of this disability, causing parents to seek a variety of conventional and unconventional treatments. It also has led to many questions. What are the symptoms? What is the cause? How is it diagnosed? How is it treated? What are the impacts? While many of these questions have been explored, others have been the subject of few investigations. For example, several studies have examined the impact on the ADHD child (Barkley, Anastopoulos, Guevremont, & Fletcher, 1991; Weiss, 1994). However, few have examined the impact on the family. The questions this study will examine are (1) What do parents perceive as the impact of parenting an ADHD child on personal and family functioning? and (2) What strategies are

families using to cope with the ADHD behavior and the stress related to it?

Symptoms typically associated with ADHD are an inability to sustain attention, impulsivity, distractibility, difficulty concentrating, and poor monitoring skills (Linden, Zalenski & Newman, 1989). ADHD is also often associated with extreme temperamental characteristics such as negative mood, short persistence, low frustration tolerance, excitability, and a quick temper (Linden, Zalenski, & Newman, 1989). Comorbidity or coexistence with other disorders such as learning disabilities, depression, and conduct disorder is also common (Biederman, Newcorn, & Sprich, 1991).

This disorder was first described in 1902 (Still) as a cluster of behavioral symptoms which included hyperactivity, poor attention, conduct disorders, and learning problems. Still hypothesized that these symptoms were due to organic causes. As early as 1937 (Bradley) medication was used to treat this disorder, which was at the time labeled Minimal Brain Dysfunction (MBD). Other labels describing these characteristics followed, including: minimal brain damage syndrome, developmental hyperactivity, hyperkinetic impulse disorder, hyperkinetic reaction of childhood, attention deficit disorder with or without hyperactivity, and attention deficit hyperactivity disorder (ADHD) (Weiss & Hechtman, 1986).

A landmark study on the cause of ADHD using positron emission tomography (PET) brain imaging on adults revealed that the rate at which the prefrontal cortex of the brain used glucose was lower in those who had ADHD (Zametkin, et al. 1990). The prefrontal lobe is responsible for "attention span, concentration, judgement, activity level, critical thinking and impulse control" (Amen, Paldi, & Thisted, 1993, p. 1080).

Amen et al. (1993) found similar results in examining ADHD children. They conducted a study of 54 children and adolescents who had been diagnosed as having ADHD using single-photon-emission computed tomography (SPECT) brain imaging. Eighty seven percent of the children diagnosed with ADHD had either decreased activity in the prefrontal cortex or prefrontal deactivation with intellectual stress. Only 5% of the control group had this brain pattern. These studies plus adoption and drug response studies have convinced many researchers that ADHD is a neurobiological condition (Children and Adults with Attention Deficit Disorders [CHADD], 1993).

While researchers are using PET and SPECT imaging in experiments, it is still not a part of diagnostic procedures (CHADD, 1994). Currently, diagnosis for ADHD is a multifaceted process which generally includes: a physical exam; neurological screening; medical, educational, and behavioral history; social and medical history of parents;

parent, teacher, and child standardized questionnaires used to determine current functioning and whether indicators of ADHD are present; intelligence testing and assessment of academic, developmental, social, and emotional skills; clinical interviews; and observations of the child (Hunsucker, 1988). To be diagnosed with ADHD, a child must experience symptoms that are more extreme than what would be expected for his or her age and symptoms must be evident in a variety of settings. In addition, symptoms must have been evident before the age of seven and there must be a duration of symptoms for at least six months (Shaywitz & Shaywitz, 1984).

It is estimated that 3% to 5% of American children have ADHD (CHADD, 1993) making it one of the most common disorders. Due to the pervasiveness of the disability and the long term outcomes for ADHD children, it is also considered to be one of the most debilitating of childhood disorders (Barkley, 1981; Trites, Dugas, Lynch, & Ferguson, 1979). One longitudinal study (Barkley, Fischer, Edelbrock, & Smallish, 1990) which followed 123 ADHD children over a period of eight years into adolescence found that 80% of these children still qualified for a diagnosis of ADHD while 60% also qualified for either an oppositional defiant disorder (ODD) or conduct disorder (CD). In addition, the ADHD children in this study were three times more likely to have failed a grade in school or been suspended. The ADHD

children also dropped out of school or were expelled eight times more frequently than the control group. Children with ADHD are also reported to have a significantly higher rate of delinquency in adolescence (Barkley, Anastopoulos, Guevremont, & Fletcher, 1992).

These behaviors and consequences cause stress in the lives of children, parents, and teachers. One study conducted on 104 ADHD families using the Parent Stress Index (PSI) showed that the average stress for parents with ADHD children was above the 90th percentile (Anastopoulos, Guevremont, Shelton, & DuPaul, 1992). Several variables influenced the degree of stress including the severity of ADHD, the child's and mother's health status, the child's oppositional-defiant behavior, and the psychopathology of the mother (Anastopoulos et al, 1992). Other indicators of stress are the higher divorce rates reported among parents who have ADHD children (Barkley, Fischer, Edelbrock, & Smallish, 1990).

ADHD behaviors also greatly impact parent-child interactions. ADHD children are reported to be more noncompliant and negative than peers (Mash & Johnston, 1982) while mothers of ADHD children are reported to be more negative, more demanding, and more controlling than mothers of children who do not have ADHD (Barkley, Anastopoulos, Guevremont, & Fletcher, 1992). Compared to control groups, mothers of ADHD children view their child's behavior as more

unstable and themselves as having less control over this behavior (Sobol, Ashbourne, Earn, & Cunningham, 1989).

As expected, studies confirm that self-esteem is lower in parents who have an ADHD child, with parents of ADHD children exhibiting more self blame than control groups (Mash & Johnston, 1983b). Parents with ADHD children also indicate they are more socially isolated and have fewer extended family contacts than families without ADHD and that the contacts that they have are less helpful (Mash & Johnston, 1983; Cunningham, Benness & Siegel, 1988).

Parents seek a variety of treatments for their children as a way of coping with this disorder. One of these treatments is the administration of stimulant medications. Medication has a positive impact upon 70% to 80% of ADHD children in the areas of attention, impulsivity, ability to stay on task, frustration level, and compliance (CHADD, 1993). These changes generally are seen with the first dose of medication and result in an immediate positive change in parent commands and negativity (Barkley, Karlsson, & Murphey, 1984; Barkley, 1989; Barkley, Karlsson, Pollard, & Murphey, 1985).

Other conventional treatments include parent education, behavior management training, therapy, self control training for the ADHD child, and communication training. In addition to these more accepted practices, a number of unconventional treatments are being utilized to treat ADHD.

Statement of Purpose

The purpose of this research was (1) to describe parental perceptions regarding the impact of ADHD child behavior on personal and family functioning and (2) to describe parental perceptions regarding strategies used to cope with the ADHD behavior and the stress related to it. This was accomplished through multiple case studies and focus groups.

ADHD affects a large number of children. In Montana alone, if we consider that 3% to 5% (CHADD, 1993) of the population of 222,104 (1990-census) children ages birth through age 18 are estimated to have ADHD, then this problem would affect between 6,663 and 11,105 children and their families. Although many studies exist that examine ADHD (1,118 in the psychological literature data base alone), few studies (9 studies in the psychological literature data base) exist that examine the impact of ADHD on families. We do know from previous studies that parents of ADHD children score in the 90th percentile on one stress inventory and that the child's characteristics can explain the greatest variance (Anastopoulos, Guevremont, Shelton, & DuPaul, 1992). However, specifically what these stressors are is unknown. We know even less about how parents cope with an ADHD child. While there are many studies which examine various interventions such as medication and parent

training, we know little about the day-to-day modifications, adaptations, and stress relievers that parents are using. Finally, only one study (Weiss, 1990) exists that specifically examines parental perceptions of ADHD. While the other studies reviewed were based upon parental reports, it was the researcher who designed the inventories and questions and who decided the degree and level of stress. Little is known about how parents themselves perceive the stress and whether they may identify other areas of stress that were not included in the instruments. Also, in all of the studies reviewed, researchers gathered all their information at a single point in time. Thus, we do not know if daily variables in the parents' lives may cause them to perceive stress differently on different occasions. Therefore, Weiss (1990) recommends further in-depth study regarding stress and coping strategies used by ADHD parents.

This study obtained detailed information from 14 parents who have an ADHD child. Information from three of these participants was obtained through multiple in-depth interviews. Two of these parents also participated in the focus groups. Focus groups alone were used to obtain information from the other 11 families. A general interview guide approach, as described by Patton (1990), was used to gather information during the interviews. A nondirective method with limited questions and probes was utilized in the focus groups (Morgan, 1988). The categories investigated

were: parental view of the child and ADHD, history and treatment of the disorder, influence of ADHD upon family relationships and organization, coping strategies employed by the family, and the influence of others on the parents' ability to cope with ADHD. Sample questions are included in Appendix C. However, the evolution of questions while one is doing the research is one key characteristic of naturalistic research (Ely, Anzul, Friedman, Garner, & Steinmetz, 1991). As Ely et al. (1991) state, "the questions shift, specify, and change from the very beginning in a cyclical process as the field logs grow, are thought about, analyzed, and provide further direction for the study" (p. 31). In many cases, my role was as a listener, asking clarification questions and providing reflective statements.

In conclusion, although ADHD is one of the most frequent, debilitating childhood disorders (Barkley, 1981; Trites et al., 1979), severely impacting family relations (Weiss, 1990) and parental stress (Anastopoulos, et al. 1992), we know relatively little about it. What is the impact of ADHD upon the family? What specifically are the stressors? How do parents cope with the ongoing high levels of stress when raising an ADHD child? This descriptive work will provide valuable information and strategies to parents who have ADHD children. It will also allow their voices to be heard by counselors, doctors, teachers, and others

working with families who have ADHD children. Intimately knowing about the experiences of a few ADHD families will aid these professionals in being more understanding and realistic in assisting these families to discover tools and ways of coping.

Definitions

For the purposes of this study I used the following definitions.

attention deficit hyperactivity disorder (ADHD) - a neurobiological disorder characterized by impulsiveness, hyperactivity, and inattentive behavior which is diagnosed by a physician (CHADD, 1993)

coping - "efforts to manage demands that tax or exceed the person's resources" (Lazaras, 1994, p. 327)

focus group - a group of peers brought together to share diverse viewpoints and thoughts regarding a topic which is selected by the researcher (Morgan, 1988)

individual education plan (IEP) - "Written documentation required by P.L. 94-142 for every child with a disability; includes statements of present performance, annual goals, short-term instructional objectives, specific educational services needed, relevant dates, regular education program participation, and evaluation procedures; must be signed by parents as well as

educational personnel" (Heward & Orlansky, 1992, p. GL-8).

perception - "The process by which meaning or interpretation is attached to experiences" (Eggen & Kauchak, 1992, p. G-10).

Section 504 of the Rehabilitation Act of 1973 - A law which states "no otherwise qualified individual with handicaps in the United States . . . shall, solely by reason of . . . handicap, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance" (U. S. Department of Education, p. 1).

Section 504 plan - an individualized plan listing accommodations which assist a child who qualifies under Section 504 to be successful in school

stimulant medication - medication prescribed by a medical doctor for the purpose of controlling ADHD symptoms

stress - "A particular relationship between the person and environment that is appraised by the person as taxing his or her resources and endangering his or her well being" (Lazarus & Folkman, 1984, p. 14).

stressor - An event or situation which may lead to stress

therapeutic levels of medication - a dosage of medication which gives the optimum benefit with the least amount of side effects

triangulation - "combination of methodologies in the study of the same phenomena or programs" (Patton, 1990, p. 187)

Literature Review

Parenting Stress and ADHD

According to several studies, families with ADHD children experience significantly higher stress than control families without special need's children (Breen & Barkley, 1988; Fisher, 1990; Anastopoulos, et al. 1992). Families with ADHD children score higher on stress inventories (Anastopoulos, 1992), have higher divorce rates (Barkley, Fisher, Edelbrock, & Smallish, 1990), and parents indicate they have more depression (Brown & Pacini, 1989) and more negative parent-child interactions (Mash & Johnston, 1982) than non-ADHD families. The following section will examine the current research regarding parental stress in families with ADHD children. Family interactions, specifically parent-child interactions, will also be examined. All the studies reported in this section are quantitative, except one. I will review this study separately. See Table 1 for a summary of the studies reviewed.

A few researchers have conducted many of the studies. Russell Barkley, for example, was involved in eight of the articles reviewed for this section. Researchers who had

previously worked collaboratively with him conducted several of the other studies, resulting in very similar methodologies.

Although the studies reviewed refer to the ADHD child by different labels including hyperactive and attention deficit disorder with hyperactivity, all the studies included used similar methods to determine the label. This difference in terminology does not, therefore, refer to different populations but rather to the term that was currently being utilized at the time the study was written. For this review I will use the terms interchangeably.

Several studies compared children with ADHD to "normal" peers. By "normal" the authors were referring to children who did not exhibit ADHD or any other serious medical or behavioral problems.

Table 1

Summary of articles relating to parenting stress and Attention Deficit Hyperactivity Disorder

Quantitative articles

Authors	Title/Date	Subjects	Methods	Results
Anastopoulos Guevremont Shelton & DuPaul	Parenting stress among families of children with ADHD 1992	104 ADHD children & parents	Standardized interviews and questionnaires	Stress in the 90th percentile for ADHD parents

Table 1, continued

Authors	Title/Date	Subjects	Methods	Results
Baker	Parenting stress & ADHD: A comparison of mothers & fathers, 1994	20 sets parents and ADHD children	Standardized questionnaires	Parenting stress similar for mothers and fathers
Barkley	Hyperactive girls & boys Stimulant drug effects on mother-child interactions 1989	40 ADHD children	Standardized observations	Boys less compliant more negative than girls, praised more, medication improved behavior for both sexes
Barkley Fisher Edelbrock Smallish	The adolescent outcome of hyperactive children diagnosed by research criteria 1990	123 ADHD 66 normal children	Clinical assessment	60% of ADHD children were CD or ODD 8 years later, parents of ADHD children higher divorce rate
Barkley Karlsson Pollard	Effects of age on the mother-child interactions of ADD-H & normal boys 1985	60 ADD-H boys and mothers, 60 normal boys and mothers	Standardized observations	ADD-H boys more negative, less compliant, their moms gave more commands, were more controlling, more pronounced with younger children
Barkley Karlsson Strzelecki Murphey	Effect of age & Ritalin dosage on mother-child interactions of hyperactive children-1984	54 ADHD children & mothers	Standardized observations	Older children more compliant & positive their mothers less controlling, all age groups improved with medication
Befera Barkley	Hyperactive & normal girls & boys: mother-child interaction, parent psychiatric status & child psychopathology-1985	30 ADHD & 30 normal children	Standardized observations	ADHD children more non-compliant, negative, mothers of ADHD children more negative, more depressed

Table 1, continued

Authors	Title/Date	Subjects	Methods	Results
Breen Barkley	Child psychopathology & parenting stress in girls & boys having ADD-H 1987	13 ADHD boys, 13 ADHD girls, 13 clinic referred girls, 13 normal girls	Standardized questionnaire	Few differences in symptoms of ADHD in girls or boys parenting stress same for ADHD girls & boys, clinic referred girls
Brown Pacini	Perceived family functioning marital status & depression in parents of boys with ADD-H-1989	51 ADD-H boys, 34 clinic controls	Standardized questionnaire	ADD-H families felt family environments less supportive, more stressful, parents more depressed
Campbell	Mother-child interaction: A comparison of hyperactive learning disabled & normal boys 1975	13 ADHD boys, 13 LD boys, 13 normal	Standardized observations questionnaire	ADHD boys more problem behaviors mothers more controlling
Cunningham Barkley	Interactions of normal & hyperactive children with mothers in free play & structured tasks-1979	20 ADHD & 20 normal boys & mothers	Standardized observation	Mothers of ADHD boys more negative controlling, & structured
Cunningham Benness Siegal	Family functioning time allocation parental depression in the families of normal & ADHD children 1988	26 two parent ADHD families 26 two parent normal families	Standardized questionnaire	Mothers of ADHD children more depressed, fewer, less helpful extended family contacts
Lahey Russo Walker Piacentini	Personality characteristics of the mothers of children with disruptive behavior disorders-1989	13 CD children 22 ADD-H children	Diagnostic interview	CD linked to maternal personality disorder, ADD-H was not

Table 1, continued

Authors	Title/Date	Subjects	Methods	Results
Lahey et al.	Psychopathology in the parents of children with conduct disorder & hyperactivity 1987	18 ADD-H, 14 CD, 23 ADD-H & CD children	Diagnostic interview	CD linked to parental pathology, ADD-H was not
Mash Johnston	Comparison of mother-child interactions of younger & older hyper-active & normal children-1982	43 ADHD, 53 normal children & mothers	Standardized observation	ADHD children more negative, non-compliant, asked more questions. Mothers more directive, less responsive, more pronounced with younger children
Mash Johnston	Sibling interactions of hyperactive & normal children-1983	23 ADHD & 23 normal boys and siblings	Standardized observation maternal report	Dyads with ADHD children higher degree of conflict mothers more stressed, lower self esteem
Mash Johnston	Parental perceptions of child behavior problems, parenting self esteem & mothers reported stress in younger & older hyper-active & normal children-1983	40 ADHD 51 normal families	Standardized questionnaire	High stress in ADHD families, higher stress with younger children
Prinz Myers Holden Tarnowski Roberts	Marital disturbance & child problems: A cautionary note regarding hyperactive children-1983	23 ADDH boys	Standardized checklist	Marital conflict not related to ADDH, boys aggression, or conduct problems at school
Porter O'Leary	Marital discord & childhood behavior problems-1979	64 clinic referred children	Standardized questionnaire	Marital hostility was related to behavior problems in boys not girls
Sobal Ashbourne Earn Cunningham	Parents' attributions for achieving compliance from ADDH children 1989	91 parents	Standardized questionnaire	Mothers of ADDH children viewed child's behavior as being more unstable

Table 1, continued

Authors	Title/Date	Subjects	Methods	Results
Tallmadge Barkley	The interactions of hyperactive & normal boys with their fathers & mothers-1983	18 ADHD & 18 normal boys & parents	Standardized observations	ADHD boys less compliant parents more directive, no significant difference mothers and fathers
Traver-Behring	The mother-child interactions of hyperactive boys & their normal sibling-1985	16 mothers with 1 ADHD, 1 normal child	Standardized observation question-naire	ADHD boys more off task, less compliant, less responsive mothers responded to ADHD & normal child in same way
Qualitative Article				
Weiss	The impact of an attention disordered child on family life: The parent's perspective. 1990	12 married couples with an ADHD child	Open ended interviews	ADHD child has a major impact on the family.

Impact of ADHD on Parenting Stress

Anastopoulos, et al. (1992) provide the most comprehensive examination of parental stress in relation to ADHD. Their study examined 104 ADHD children under the age of 12 (87 boys and 17 girls) and their mothers. Parent interviews; child behavior rating scales; assessment of the child in relationship to ADHD severity, aggressive behavior, internalizing problems such as depression, peer relations, health status, medication status, and special education status; child demographics; assessment of the mother's health, depression, overall psychopathology, and

psychological stress; assessment of family demographics and socioeconomic status; and assessments of problems exhibited by other family members were all examined using a variety of instruments. The Parent Stress Index (PSI) which was used to assess overall stress levels indicated that parenting stress scores averaged above the 90th percentile. The severity of the child's behavior, primarily the amount of aggression and oppositional behavior accounted for 37% of the variance. Other major predictors of variance were parent pathology, child health, and the mother not working out of the home. Mothers who did not work outside the home reported greater parental stress. Although some studies have shown that external stressors may be influencing both the family stress and the hyperactivity (Gillberg, Carlstrom, & Rasmussen, 1983), environmental stress accounted for only 4% of the overall variance in this study. Environmental or external stress included marital status, the number of children in the family, maternal relationship to the biological father, maternal stress unrelated to the parent-child relationship, and psychiatric and medical problems in other family members. There was, however, a trend toward more stress in single parent families which accounted for 4% of the variance.

While Anastopoulos et al. (1992) examined only maternal stress; Baker (1994) examined both maternal and paternal stress. In studying 20 married couples with an ADHD child,

he found no difference between the mother and father in their rating of child behavior with both viewing the child's behavior as a severe problem. However, when compared to the father, the mother stated that the child's behavior caused more parental stress. As in Anastopoulos's et al. study Baker conducted a regression analysis to determine the contributions to parenting stress. Similar to their findings, the total problem behavior of the child was the strongest indicator of stress, accounting for 28% of the variance. The number of years married accounted for 9% of the variance, with being married fewer years being associated with elevated stress. Eight percent of the variance was due to socioeconomic status (SES), with those parents who had higher SES indicating more stress. Stress based on gender had a limited influence, accounting for only 6% of the variance.

This research confirmed the earlier findings of Mash and Johnston (1983b) who studied 40 families with a hyperactive child and 51 families with "normal" children. They found that child characteristics accounted for 74% of the variance between groups. They found no significant difference in external stressors between the two groups in their study. This again showed that situational factors such as low paying jobs, living in poor neighborhoods etc. were not the predominant problems causing high stress ratings in parents with hyperactive children. Both ADHD

mothers and fathers in the study viewed themselves as less skilled and knowledgeable than the parents with normal children with this feeling escalating as children got older. ADHD parents also showed that they derived less comfort and value from parenting than parents of normal children. The mothers in the study indicated they had significantly more parenting stress than the mothers of normal children, with younger ADHD children being considered more stressful and their mothers more depressed and more self-blaming.

Parenting stress also appears to be impacted by sibling interactions. Mash and Johnston (1983a) examined sibling interactions between 46 sibling dyads, 23 without disabilities and 23 where one sibling had ADHD. They found that sibling interactions when one child had ADHD was characterized by four times more negative behavior when there was no adult supervision and twice as much when supervised by mothers. This amounted to 10% of all interactions between ADHD children and their siblings being negative. Neither the sex nor the age of the sibling influenced the amount of negative interactions. However, young hyperactives were more negative than older hyperactives during supervised play. There was also a correlation between the mother's report of self-esteem and stress and the degree of negative behavior and amount of independent play exhibited by the child, with a positive correlation between negative behavior and stress, and an

inverse relation between independent play and stress (Mash & Johnston, 1983a).

These studies indicate that parents experience increased stress when parenting an ADHD child and that child variables can explain the largest amount of variance. Stress is increased with a greater degree of hyperactivity, a younger ADHD child, increased display of aggression and oppositional behavior by the child, and sibling rivalry. External issues unrelated to the child's hyperactivity, such as SES, number of children in the family, and psychiatric and medical conditions in fathers and siblings do not seem to have a great impact on the parental stress level in the studies examined. However, single parents and those mothers not working outside the home indicated higher stress than their counterparts with ADHD children.

Marital Relations and ADHD

Other indicators of stress are the higher divorce rates among parents who have ADHD children. One 8 year longitudinal study found that compared to the control group more than three times as many mothers of ADHD children were separated or divorced from the child's biological fathers (Barkley, Fischer, Edelbrock, & Smallish, 1990). Brown & Pacini (1989) compared ADHD families to not only a control group of nondisabled children but also other clinic-referred children who were experiencing learning disabilities or developmental disorders. They also found an increased

incidence of separation and divorce in the families with ADHD children.

Studies conflict on whether ADHD impacts marriages or whether marital problems impact ADHD, with one study finding that the amount of aggression observed by teachers at school and by parents at home was not correlated to marital adjustment or discord (Prinz, Myers, Holden, Tarnowski, & Roberts, 1983). However, other studies have suggested a positive relationship between marital conflict and the amount of aggression displayed by ADHD boys (Porter & O'Leary, 1980; Hetherington, 1979).

Maternal and Paternal Pathology in Relation to ADHD

Several studies have also linked ADHD to maternal depression (Sobol, et al. 1989; Cunningham, et al. 1988). While generally researchers have studied only mothers, Brown and Pacini (1989) examined both maternal and paternal depression in 85 ADHD and ADD children, 34 nondisabled children, and 34 other children referred to the clinic. They used depression inventories that are highly correlated with clinical depression. Both mothers and fathers of ADHD and ADD children rated themselves as significantly more depressed than the clinic controls or the controls without children with disabilities. The parents who stated that there were disturbed interpersonal relationships in the family rated themselves higher in depression. These parents

indicated that their family environments were unsupportive, stressed, high in conflict, low in autonomy and expressiveness, and lacked cohesiveness. The depression appeared to impact mothers and fathers differently. When fathers stated they were depressed they also indicated an increased frequency of family activities and greater parental control over children. However, depression in mothers was related to a decrease in family activities. Parental depression also had an impact on the way that parents perceived their children. Those who were depressed experienced greater parenting stress, less acceptance of their child's behavior, and viewed their child as more demanding (Breen & Barkley, 1988).

Although many studies have found a correlation between pathology in parents and ADHD in their children, two studies which separated those children who had ADHD from those displaying both ADHD and conduct disorder (CD) have found that maternal pathology as defined by the Diagnostic and Statistical Manual (DSM III) is no greater in mothers who have ADHD children than in control groups (Lahey, Russo, Walker, & Piacentini, 1989; Lahey, et al. 1988).

In summary, several studies indicate that mothers and fathers who have ADHD children report that they have more symptoms of depression than controls. This is particularly true for those families who are engaged in more disturbed familial interpersonal relationships and exhibit a higher

degree of conflict. However, two studies made a distinction between those children that have only ADHD and those who have ADHD in combination with conduct disorder. It was only the ADHD with conduct disorder that was linked to higher maternal pathology.

Interactions of the ADHD Child in Comparison to Peers and Siblings

When hyperactive children were compared to nondisabled and learning disabled peers, they were found to be significantly different in the number of requests for feedback and in the number of comments regarding the tasks they were completing (Campbell, 1975). In fact, in her study, Campbell describes the typical ADHD child as conducting a running monologue while working on tasks.

Mash and Johnston (1982) concurred with Campbell's (1975) findings of high verbal activity, concluding that the hyperactive child asked significantly more questions than his or her peers. They also found that the ADHD child was more negative and noncompliant than peers at all age levels studied, but particularly at younger ages. They noted that the younger hyperactive children (ages two years 11 months [2.11] through six years 11 months [6.11]) showed negative and noncompliant behavior twice as often as older hyperactive children (ages 7.3 through 9.10) (1982). In addition, regardless of age the ADHD child had less social

involvement than would be expected for his or her age (Mash & Johnston, 1983a).

A study by Barkley, Karlsson, Strzelecki, and Murphey (1984) also found that with age, children became more compliant and exhibited less negative behavior. Mothers of older children exhibited less controlling behavior and gave fewer commands. This type of improvement is seen in normal mother-child dyads as well. With an increase in age, there also was a decrease in the mother giving positive feedback when the child complied. However, even with improvement in age, children with ADHD were distinguishable from peers, exhibiting less compliance with rules.

Researchers have also conducted studies to determine if there are sex differences in relation to parent-ADHD child interactions. In a study conducted by Befera and Barkley (1985), few significant differences in behavior were found between sexes (mean age 103.4 months) with behaviors of both ADHD boys and girls being more noncompliant, off task, and negative than their counterparts. However, in a later study by Barkley (1988) comparing younger children (mean age 71.8 months), boys were found to be less compliant and more negative than girls.

While the other studies reviewed compared the ADHD child to peers, Tarver-Behring, Barkley, and Karlsson (1985) compared the hyperactive child to his sibling. In examining 16 pairs of brothers who were within two years of age, they

found that the hyperactive child was less responsive to requests and questions, less compliant, more off task, and posed more severe behavior problems than his sibling.

It appears that regardless of family constellation, age, sex, or whether compared to peers or siblings, the ADHD child demonstrates more problems than non-ADHD children. They request more feedback, ask more questions, are less compliant, are more negative, and less involved socially. This behavior is most severe in younger children. These difficulties also seem to be most pronounced in situations that are more rule governed, demanding more restraint or compliance, such as being in public places or having visitors to the home (Tarver-Behring, Barkley, & Karlsson, 1985).

Parent-Child Interactions: Children with ADHD Compared to Non-ADHD

Campbell (1975) found that the mothers of the hyperactive boys attempted to control their children by giving significantly more suggestions about impulse control, more nonspecific suggestions, more disapproval, and more praise and urging to complete a task than the mothers with learning disabled or normal children. The hyperactive child was more impulsive, more disorganized, and more dependent on parental interaction to complete tasks than either the learning disabled child or the normal controls.

Further studies by Cunningham and Barkley (1979) supported these results indicating that mothers of hyperactive boys were more controlling than mothers of nondisabled children, giving their children twice as many commands. This was especially evident in task situations where ADHD children were found to be more active, less compliant, and less frequently on task. Mothers of ADHD children were also less responsive to the child's initiations and were less involved in social interactions with their child than the controls. The mothers of normal children interacted more positively with their child, visiting with them, asking questions, and praising them. This led Cunningham and Barkley to conclude that "mothers of overactive boys appear more critical and disapproving and seem to have acquired a generalized negative set of expectations which adversely influence their perception of and response to the child" (1979, p. 223).

Studies with younger ADHD children supported these findings (Barkley, Karlsson, & Pollard, 1985; Mash & Johnston, 1982). These studies indicate that mothers of younger hyperactive children show significantly more negative behavior than mothers of older hyperactive children or mothers of normal children. However, it must be noted that the younger hyperactive children portray the most negative behaviors.

Although most other studies have reviewed interactions between the mother-child dyad, Tallmadge and Barkley (1983) examined interactions between the father-child dyad as well. They discovered that both parents of ADHD children were more controlling and negative than the control group and that the boys were less compliant with commands and complied for shorter periods. Noncompliant behaviors were especially evident when the child was interacting with the mother.

When looking at differences in the way mothers interact with their ADHD child based upon the sex of the child, Befera and Barkley (1985) found that there were few differences. However, hyperactive boys did receive more praise from their mothers even though there were no significant differences in behavior between the ADHD boys and girls. Barkley (1989), in a later study found that mothers were more controlling, as well as encouraging to boys. However, his study also found that the boys were more negative and less compliant than the girls in the study.

Although previous studies (Barkley, Karlsson, & Pollard, 1985; Cunningham & Barkley, 1979) found that parents of ADHD children treated their ADHD child differently from their non-ADHD child, a study by Tarver-Behring, Barkley, and Karlsson (1985) did not confirm this. They examined sibling brothers, one with ADHD and one without and found that mothers did not treat their ADHD child differently from the sibling, even though the ADHD

child was less responsive to their mothers and portrayed more noncompliance. Mothers tended to treat both the ADHD child and sibling in ways that other studies had described in relationship to normal children. In explaining this discrepancy between previous studies, two of which the authors conducted, they stated that they observed the mothers twice on the same day, once with one child and once with the other. They felt that mothers may have consciously tried to treat the boys in an equal way. Also the boys may have tried to compete with each other in being well-behaved which was portrayed by greater compliance in the ADHD child than in previous studies.

In summary, ADHD children are found to be more active, impulsive, disorganized, and dependent than their peers. They are also more noncompliant and comply with requests for shorter periods of times. Both fathers and mothers of ADHD children are found to be more controlling, to give more commands, and to be more negative than parents who do not have ADHD children. This is especially evident in younger child-parent dyads. When the number of commands increases, ADHD children display even less compliance, leading some researchers (Cunningham & Barkley, 1979) to ponder the cyclical nature of the negative parent-ADHD child interactions.

Qualitative Research on the Impact of ADHD

The previously reviewed studies were all quantitative. The only qualitative study I found regarding the impact of ADHD was an exploratory study which examined the ADHD child's impact on the family (Weiss, 1990). Weiss gathered data through 1 hour interviews with 12 married couples. She found that having an ADHD child did have a significant impact on the family. Major themes which the author identified were "the struggle" and "expectations". The struggle involved difficulties with the child's behavior, with a proper diagnosis, and with the schools. Parents reported struggles in school due to lack of accommodations, lack of teacher education about ADHD, and difficulties at home in getting children to complete school requirements such as homework. In regard to expectations, parents had problems deciding what to expect, felt a need to lower expectations, revealed disappointments over having a child different from what they had expected, and described difficulty with feelings of being judged and in dealing with the unrealistic expectations by others.

Weiss also described four major findings. First, parents had fewer social relationships as a result of having an ADHD child. This was due to several variables including the child's behavior, others disagreeing about how the child should be handled, parental exhaustion, and lack of child

care. Families reported that both neighborhood and family relations often were strained due to the child's behavior. In many cases relatives were disapproving of the use of medication and critical of the parents and child. The child's behavior also made it difficult to find and retain babysitters. In addition, parents reported that the feeling of exhaustion from raising an ADHD child caused them to seek fewer social outlets. However, while previous sources of support were sometimes terminated, some of the families made new social connections with other families who had ADHD children.

Second, parents altered their parenting to meet the needs of the ADHD child, leading to changed expectations. This sometimes led to disagreements between parents regarding what changes should occur and what form of discipline should be used.

Third, the parents' reported there was a greater need for parental supervision of the ADHD child than other children. This was due to the child being frequently bored, having difficulty in initiating activities, being unable to follow through with activities including homework and chores, and being more demanding of the parent's attention. Weiss (1990) found that the parents needed to provide an extreme amount of attention to organize and supervise the child's activities.

Fourth, the decision to medicate created an ongoing dilemma for parents. Parents experienced guilt, difficulty in achieving a therapeutic dose of medication, practical problems in working with others who must provide medication for the child, and the feelings of being judged negatively by others for giving their child medication.

Weiss's (1990) study produced valuable results. However, it could have been strengthened in several ways. Participants were interviewed in a single sitting for one hour. More time with parents would have been useful. Second, the only methodology used was individual interviewing. Using only one method causes a study to be more susceptible to errors (Patton, 1990) thus, some researchers (Denzin, 1978) advise that multiple methods be used in every study. Third, the insights and patterns discovered were not checked with the participants. Participant checks are helpful in determining the validity of data through allowing the participants to correct errors, add information, summarize, and assess the overall adequacy of what the researcher has stated (Lincoln and Guba, 1985).

Coping With ADHD

A variety of treatments have been investigated as ways of alleviating the symptoms of ADHD and to help parents and children cope with this disorder. One of the most common conventional approaches is the administration of psycho

stimulant medication (Horn, Ialongo, Greenberg, Packard, & Smith-Winberry, 1990) which researchers believe increases the concentration of chemicals to the neurotransmitters in the frontal lobe of the brain (CHADD, 1993). Two other frequently reported conventional treatments are parent training and self-control training for the ADHD child.

In addition, parents are utilizing a variety of experimental treatments for which there is little scientific support. These include: dietary interventions such as the Feingold diet which is designed to reduce allergens; megavitamins and minerals therapy; anti-motion medication to treat problems of the inner-ear; treatment to decrease the amount of candida yeast; EEG biofeedback to increase brain wave activity; applied kinesiology; and optometric vision training (Goldstein & Ingersoll, 1993).

The following sections will examine the impact of medication, self control training for the ADHD child, and family therapy as means of alleviating ADHD symptoms. All but one of the studies are quantitative. While the qualitative study does not specifically address parents' strategies in coping with ADHD, it does examine attributes of parents who successfully cope with other disabilities. For a summary of articles reviewed in this section see Table 2.

Table 2

Summary of articles relating to parental coping with Attention Deficit Hyperactivity Disordered children

Quantitative articles

Authors	Title/Date	Subjects	Methods	Results
Anastopoulos Shelton DuPaul Guevremont	Parent training for ADHD: Its impact on parent functioning 1993	36 ADHD children & mothers	50% of group received behavior management training	Reduced stress & increased self esteem in treatment group
Barkley	The effects of Methylphenidate on the interactions of preschool ADHD children with their mothers 1988	27 ADHD children & mothers	Blind placebo controlled crossover design	ADHD children on high levels of medicine increased on task behavior
Barkley	Hyperactive girls & boys: Stimulant drug effects on mother-child interactions 1989	40 ADHD children	Blind placebo controlled crossover design	Boys less compliant more negative, mothers praise boys more, both sexes improve on medication
Barley Guevremont Anastopoulos Fletcher	A comparison of three family therapy programs for treating family conflicts in adolescents with ADHD 1992	61 ADHD children & mothers	3 treatments groups	All treatments resulted in significant improvements in communication, conflict and anger. Only 5-30% showed clinically significant change
Barkley Karlsson Pollard Murphey	Developmental changes in the mother-child interactions of hyperactive boys: Effects of two dose levels of Ritalin-1985	60 ADHD boys & mothers	Blind placebo controlled crossover design	Compliance & attention increase with age, mothers less directive & controlling with older children, high dose produced improvements in child compliance

Table 2, continued

Authors	Title/Date	Subjects	Methods	Results
Barkley Karlsson Strzelecki Murphey	Effects of age & Ritalin dosage on the mother-child interactions of hyperactive children-1984	54 ADHD children & mothers	Standardized observations	Mothers less controlling, children more compliant & positive when older, all age groups improve behavior on medication
Blakemore Shindler Conte	A problem solving training program for parents with ADHD-1994	24 ADHD children & parents	3 treatments individual, group, control	Stronger treatment effects for individual therapy & for mothers
Horn Ialongo Greenberg Smith-Winberry	Additive effects of behavioral parent training & self control therapy with ADHD children 1990	42 ADHD children 18 control	3 treatments behavior management, self control, combination	No support for additive effect of treatment
Horn Ialongo Popvich Peradotto	Behavioral parent training & cognitive-behavioral self-control therapy with ADHD children: Comparitive & combined effects-1987	19 ADD-H children	3 treatments behavior management, self control, combination	Significant improvement in behavior at home, no change at school, no additive effect
Pisterman McGrath Goodman Webster	Outcome of parent mediated treatment of preschoolers with ADD-H 1989	46 ADD-H children & parents	One half received parent training	Compliance from child, parental interaction & management improved with treatment
Schachar Taylor Wieselberg Thorley Rutter	Changes in family function & relationships in children who respond to Methylphenidate 1987	38 boys & mothers	Double blind crossover design	Maternal warmth & contact increased, criticism decreased, fewer negative sibling interaction

Table 2, continued
Qualitative article

Authors	Title/Date	Subjects	Methods	Results
Naseef	How families cope successfully with a handicapped child: A qualitative study-1989	7 families	Structured interviews	Families use a variety of strategies to cope, parents use convergent methods to cope, siblings allowed to ask questions & discuss issues about handicap

Impact of Stimulant Medication upon Parent-Child Interactions

Cunningham and Barkley state that ADHD mothers have "acquired a generalized negative set of expectations which adversely influence their perception of and response to the child" (1979, p. 223). But, are negative expectations and parenting the cause of ADHD or the result of it? One way of determining this is to examine changes in parenting behavior after the child has been administered stimulant medication. Stimulant medication has been found to have a positive impact upon 70-80% of ADHD children in the areas of attention, impulsiveness, ability to stay on task, frustration level, and compliance (CHADD, 1993). A study conducted by Barkley, Karlsson, Strzelecki, and Murphey (1984) examined 54 children, ages four through ten using a double-blind, drug-placebo crossover design. The study examined mother-child interactions during both free play and in completing a task when the child had no medication and

when they had different levels of medication. Within 30 minutes after the administration of medication interactions during task situations significantly improved with the child becoming more compliant and exhibiting more on-task behavior. Parental behavior also underwent an immediate change with the mother becoming less controlling, more positive, and engaging in more nondirective dialogue. These results were not found when children were on the placebo. Using similar methodology, later studies have confirmed these results in similar age groups (Barkley, Karlsson, Pollard, & Murphey, 1985), in preschoolers ages 2 through 4 (Barkley, 1988), and in both boys and girls (Barkley, 1989).

Schachar, Taylor, Wieselberg, Thorley, and Rutter (1987) using parent and teacher interviews and rating scales, but no observation, found that maternal warmth and contact were increased and parental criticism decreased when children were on medication. There were also fewer negative encounters between the ADHD child and his siblings. However, as might be expected, the actions that parents stated they would take in regard to problem behaviors and the consistency between how mothers and fathers stated they would handle situations did not change as a result of the child receiving medication.

All of the above studies reveal more compliant behavior by the child and a corresponding change in parental behavior

when the child is on stimulant medication. This was found in spite of the fact that the studies that have been conducted all use small doses of stimulant medication with the same dosage given to all children. Since there is no consistent therapeutic dose in relationship to size or age of the child, a proper medication dosage must generally be determined through medication trials (CHADD, 1993). These studies, examined the interaction between parent and child after the child had been on medication for only one week. Observations of these interactions were conducted in a lab setting rather than a natural environment. In most cases the researchers conducted observations once and generally for 15 minutes. Researchers examined mother-child dyads in isolation from other family members in a bare room with five toys and minimal furniture present. Due to these common elements in the research design many questions regarding interactions remain unanswered, including the impact of therapeutic levels of medication on parent-child interactions in a naturalistic setting.

Other Methods of Therapy

Parent training and self-control training have been the other treatments most studied. With the exception of one study by Blakemore, Shindler, and Conte (1994) parent training has been based on learning to use contingency systems. This includes the use of behavioral observation and charting, reinforcement of positive behavior,

utilization of extinction and punishment such as time out and response cost, and behavioral contracts. Contingency systems are based on the belief that patterns of parental reinforcement are one of the causes of behavioral difficulties (Blakemore, et al. 1994).

Self-control training involves teaching the child techniques such as problem solving and self talk. In some cases this also consists of teaching skills such as muscle relaxation.

Two studies (Horn, Ialongo, Popovich, & Peradotto, 1987; Horn, et al. 1990) examined three groups of school age children (one receiving parent training, one receiving self control training, and one receiving both treatments). In the study conducted by Horn et al. (1987) all the groups showed significant improvement in the child's self-concept scores, perceived self-control, and IQ scores. Mothers in all the treatment groups stated there was a decrease in hyperactivity, anxiety, and withdrawal, but not conduct problems. However, there were no changes in the parent's attitude about discipline (authoritarianism, hostility or rejection, or democratic attitudes) the perceived support from their spouse, or the number of positive or negative contacts outside the home regardless of treatment method. Observations in the classroom revealed that regardless of treatment there was no carryover in improved behavior within this setting. An unexpected finding was that the combined

treatment did not produce greater treatment effects than either of the treatments alone. Those ADHD children who showed the most improvement had a greater internal locus of control, were more reflective, and recognized that they had problems with self-control. Mothers who had a support system outside their family showed more improvement than those that did not.

Horn's et al. (1990) subsequent study increased the number of parent training sessions and added three consultation visits with teachers. As with the previous study, parents rated the child's hyperactivity and externalizing behaviors as decreasing. According to checklists completed by the teachers there was also a significant reduction in behavior problems at school. However, there was no improvement in school behavior at the eight-month follow-up. Again, surprisingly, the combination of treatments didn't help generalize the effects or maintain treatment gains.

Anastopoulos, Shelton, DuPaul, and Guevremont (1993) also studied children in the 6 through 11-year-old age range. They found that behavior management training along with information about ADHD resulted in a significant improvement in the parent's perception of the severity of ADHD symptoms. The researchers also examined parental stress and found a significant reduction in parent stress

and enhanced parenting self-esteem when parents received behavior management training.

In studying a different age group, Pisterman, et al. (1989) found that ADHD preschoolers whose parents received training were more compliant, complying with 60% of parent commands versus 42% of parent commands before parental training. However, this was due mainly to a decrease in what the authors referred to as beta commands. These were commands that were vague or conditional and that did not offer the child an opportunity to comply. There was also a significant increase in the amount of child compliance that parents' reinforced and a significant decrease in parental directives, resulting in more positive parent-child interactions. There was no evidence of change in the amount of hyperactivity, the frequency of inappropriate behaviors, or the time the child spent on task.

Barkley, Anastopoulos, Guevremont and Fletcher (1992) studied 61 ADHD teens and their parents. They randomly assigned the adolescents to behavior management training, structured family therapy, or problem-solving and communication training. Teens reported significant improvements in communication, the number of conflicts, and the amount of anger displayed during conflicts. Adolescents also reported less anxiety, depression, withdrawal, aggression, and delinquency. This was confirmed by their parents. The mothers reported that they were less depressed

after the therapy. Again, there was no significant difference found between any of the treatments.

While the previously reported studies relied on behavior contingency, Blakemore, et al. (1994) used a cognitive-behavior style of intervention. This included learning about ADHD, the grief cycle, perspective shifting, preventive techniques, cuing by questioning, providing descriptive feedback, providing alternatives, acknowledging feelings, and anger management. Parents were randomly assigned to individual counseling or group counseling. Total stress scores were significantly lower for both groups of mothers, with a greater reduction in stress for those involved in individual sessions rather than group sessions. Stress reduction was stronger for mothers than fathers with mothers also displaying more persistent changes at follow-up.

Information in the majority of studies reviewed were based on parent, teacher, and children's reports using standardized instruments. When observations occurred they were in a clinical setting or educational setting. The self reports and observations resulted in significant changes being cited in each of the studies. In studies which examined different types of treatment, there appeared to be no statistical difference between these treatments.

However, studies may reveal statistical significance but not reveal clinical significance. When statistical

significance occurs, it means that this finding was unlikely to have occurred by chance. Clinical significance means that the magnitude of change is statistically reliable and that this change moves clients into the range of normality. Researchers examined clinical versus statistical significance in three of the studies. In studying adolescents, researchers (Barkley, Guevremont, Anastopoulos, & Fletcher, 1992) discovered that 70% to 95% showed no clinically significant change in family conflicts or degree or frequency of anger. In addition, 80% to 95% of the subjects remained deviant after treatment. Horn et al. (1990) also found that while there was significant improvement in ADHD subjects at the end of the treatment, in all but one case ADHD subjects were still significantly different from the non-ADHD controls at the end of treatment. In examining parenting stress, Anastopoulos et al. (1993) found there was no clinical significance in 74% of the parents regarding stress and 63% regarding their sense of competence. Therefore, while parent training, self control training, communication training, and family therapy all produce statistically significant results, there is little evidence of clinically significant results.

Qualitative Research on Coping

Although I was unable to find any qualitative studies which specifically addressed coping in families with ADHD children, I did find one study that examined coping in

families with children having other disabilities. Robert Naseef (1989), interviewed seven families that professionals identified as coping successfully with having a child with a disability. The disabilities represented in his study were deafness, blindness, autism, learning disabilities, cerebral palsy, chronic illness, and emotional disturbance. Three generalizations were found: these families had a large repertoire of coping mechanisms, the parents had convergent accounts of how they coped, and the parents allowed the siblings to freely question and discuss issues regarding the child with a disability (Naseef, 1989, p. 13).

Conclusion

Although, it is presumed that when parents gain more control over their child they experience less stress (Anastopoulos, 1993) and are therefore able to cope better, this was examined in only three of the studies. Since previous studies have shown that the greatest source of stress for ADHD parents is variables within the child, it is logical to conclude that treatment of the ADHD symptoms through medication may relieve parental stress and therefore be an important coping technique. Current studies do reveal improved child behavior, including greater compliance to parental commands, reduced negativity, and more time on-task. Parents also reduced negative commands and interacted more positively with the child when the child was on

medication. However, none of these studies examined the long term effect of medication on parent-child relations.

Parent training, self control therapy, and family therapy are also treatments used to cope with ADHD. However, studies on these methods appear to produce few clinically significant results in child behavior, family relations, or parental stress. CHADD recommends (1993) that multi modal treatment is necessary in treating ADHD. This may include parent training, educational interventions, counseling for the child and family, and medication therapy. In spite of these recommendations, none of the reviewed studies examined this combination of interventions. In addition, the studies did not examine the day-to-day stress relievers or coping mechanisms that parents are using. One qualitative study which examined families who were successfully coping with other disabilities suggests that having a broad repertoire of coping mechanisms, parents sharing convergent methods of coping and siblings being allowed to discuss the disability freely are indicators of successful coping. However, we do not know if this is true for ADHD families.

CHAPTER 2

METHODS AND PROCEDURES

Introduction

This dissertation was based on qualitative case study methods which (1) described parental perceptions regarding the impact of ADHD child behavior on personal and family functioning and (2) described parental perceptions regarding strategies used to cope with the ADHD behavior and stress related to it. Methods included multiple in-depth interviews with three families who have an ADHD child and three focus groups each consisting of three to six parents with ADHD children.

In determining a research plan I examined the definitions, characteristics, strengths, and weaknesses of both qualitative and quantitative designs to determine what would fit best with the goals of this investigation. I then based the decision about which design to use on which was most appropriate for investigating the problems for this study. This led me to choose a qualitative design.

Qualitative research allows an in-depth, detailed investigation which seeks to gain a wealth of information from the viewpoints of a few people (Patton, 1990). Although qualitative methods may be found in both quantitative and qualitative research, it is in recognizing

that each researcher brings a point of view to the research and "viewing knowledge as local and context-bound and encouraging multiple meanings of a situation without encompassing the explanation of those meanings in a single generalization" (Krathwohl, 1993, p. 323) that constitutes a qualitative point of view (QPV). In addition, when one uses a QPV, one's questions evolve as one conducts the research which is occurring concurrently with the analysis. This is aided by not being constrained to predetermined categories but instead discovering the patterns and themes that emerge from the data. The emergent nature of the research and also the lack of a standardized instrument means that the researcher is "the instrument." Therefore, the validity of the research is greatly impacted by the researcher's competence (Patton, 1990). In qualitative research, the researcher addresses bias by first publicly admitting his or her biases and then planning ways to minimize them. While qualitative research provides rich understanding that is often unattainable through other means, the small numbers and lack of a standardized instrument make it more difficult to generalize to larger samples.

I decided to use a qualitative research design for this study for several reasons including: the ability to answer questions that required in-depth information based upon the perspectives of the participants, the need to examine the

whole of the experience, and the importance of conducting the research over a period of time.

Except for one study, all the research available regarding families with ADHD children is quantitative. For example, the Parent Stress Index (PSI) was used to examine the degree of stress ADHD parents experience. The PSI is a standardized instrument which reports a quantitative level of stress. This has provided valuable information about the degree of stress experienced and the fact that child characteristics account for the greatest variance in determining the cause of this stress. However, I found that several questions remained unanswered regarding the impact of ADHD; what the specific stressors were, how the stress affected the day-to-day life of the ADHD family, and how parents coped with this stress. To answer these questions I needed to conduct an in-depth investigation to gain the perspectives of parents who have ADHD children.

Qualitative research allows those whom researchers are studying to speak for themselves (Ely et al., 1991) which in turn allows the researcher to understand the construction of reality as the subjects have created it (Crabtree, Yanoshik, Miller, & O'Connor, 1993). The need to do this has led to what Parnel Wickham-Searl (1992) describes as a switch in paradigms in studying parents who have children with disabilities. The purpose of the new paradigm being to understand the experiences of these parents through their

eyes asking for their interpretations rather than through the "explicitly, ostensibly, objective perspectives provided by professionals" (p. 251).

Qualitative research also allowed me to examine the whole of the experience rather than compartmentalizing it (Ely et al., 1991). This was especially crucial in my project which studied families. "Family life is a very complex and interdependent human experience, which does not easily lend itself to the identification and isolation of single sets of variables as is necessary in experimental research" (Weiss, 1990).

Comprehension of how parents perceived the impact of ADHD and coping techniques, not only required an in-depth investigation, but required that information be gathered over a period of time. Intensive field work over a period of time assisted in the development of rapport between myself and the participants which was necessary so that the subjects felt comfortable sharing sensitive information about their lives. Multiple sessions also allowed emotions and thoughts to be raised to the participants level of consciousness so they could be articulated. In addition, more than one session allowed exploration of parents' perceptions of stress and coping over a period of time. Qualitative research allowed me the time needed to "gain access to levels of life or groups of people that are simply unavailable without the extended `time in the field' typical

of participant observation and in-depth interviewing" (Becker, 1966/67, p. 14).

In conclusion, only through using a qualitative methodology, which utilized in-depth information and adequate time in the field as a way of grasping the subject's perspectives, was I able to adequately achieve the purpose of this study.

Establishing Trustworthiness

Qualitative researchers believe that all researchers have biases or values. Instead of holding these covertly, they believe that one must acknowledge these biases and take conscious account of them (Lincoln & Guba, 1985). In the following section, I will describe my personal and professional background and experiences in relation to ADHD, how this has created personal bias of which I am now conscious, and how I tried to minimize its effect in my research through open-ended questions, participant checks, objective readers, and the triangulation of data.

In qualitative research the researcher is "the instrument" (Merriam, 1988). "Validity in qualitative methods therefore hinges to a great extent on the skill, competence and rigor of the person doing fieldwork" (Patton, 1990, p. 14). Therefore, I will also describe my qualifications to perform this study.

Experience and Assumptions Regarding ADHD

My most extensive experience as well as knowledge about ADHD comes from parenting two ADHD children and having an ADHD spouse. Upon receiving the first official ADHD diagnosis five years ago, I began the search to discover what experts knew about this disability. This search led me to read articles and books, attend a college course, participate in state and national workshops on ADHD, and work with an ADHD support group. While my experiences as a parent of ADHD children have caused me to acquire first hand knowledge and to seek knowledge from others, they also have caused me to have some biases. First, I have found that even though my children are currently on medication, raising ADHD children is extremely stressful. Second, my personal experience has resulted in the belief that outside agencies such as schools and counselors may at times aggravate rather than relieve this stress. Third, I view myself as an authoritative parent. This involves a belief that children and adults need to share power and control with children given the responsibility to make decisions as well as mistakes. I believe that children should be treated respectfully at all times even when being disciplined and that positive self-esteem is a crucial goal of parent-child relationships. I view effective communication as another key ingredient to successful parent-child relationships. I

also believe that one of my roles as a parent is to establish an environment where children are safe, stimulated, nurtured, encouraged, and modeled appropriate behaviors. Previously I had believed that by using these methods most difficult situations could be overcome. However, I have found that with ADHD children this is not always true.

Professionally, I am an Assistant Professor in the Education Department and the Director of Early Childhood Education at Western Montana College. As an early childhood professional, I believe in the importance and crucial role played by parents, limiting behavior altering medication, the important role of the environment in shaping behavior, and the need for positive discipline approaches rather than those based on power-assertion. I have found that some beliefs in early childhood regarding what are best practices for children and families have been in conflict with those practices viewed as most effective by researchers in the area of ADHD. These have been most evident in regard to the role of the environment, behavioral approaches to discipline, and the role of medication (Bredekamp, 1987).

To guard against both my professional and personal biases affecting those being interviewed, I did not specifically ask about sources of stress unless the participants first indicated that they were experiencing stress. Instead, I began with a general question. In the

individual interviews I asked participants to tell me about their child. In conducting the focus groups I asked parents to describe an experience with their ADHD child. I also tried to control bias by asking neutral questions. For example, "What has been your experience with schools in relation to your ADHD child?" rather than "What problems have you encountered with schools in relation to your ADHD child?" Since questions emerged during the course of the interview, the transcripts were later reviewed by an objective reader to determine if non-neutral questions were asked or feedback was given. The transcripts for all the focus groups as well as the transcripts for all the interviews for one of the case studies were analyzed. The reader had a doctorate degree and 19 years experience teaching language arts classes, courses on intercommunication skills, and courses on exceptional children. The results of the evaluation are included in Appendix A.

Participant checks were also used to examine the validity of data, patterns discovered, and conclusions for the case studies (Lincoln & Guba, 1985). These ongoing checks allowed participants to add information, summarize, and assess intentionality. I also asked each of the participants involved in the case studies to read the case study to detect errors and assess overall adequacy. If a participant and I disagreed regarding whether an error had

occurred I planned to report both accounts to the reader. However, this did not occur. Following are the comments and corrections made as a result of the participant checks.

Sue stated, "I didn't see any distortions or exaggerations. It was not patronizing or overly sympathetic. It accurately portrayed my feelings and difficulties." A minor correction was made in the case study regarding her son breaking a knuckle rather than a finger.

Sabrina also stated that the case study was "accurate" and material was treated in a "matter of fact" way. She said, "I laughed and cried as I read it. By the end of the case study I felt an inner calmness." One minor correction was made in the case study. I had stated that a friend had been a childhood friend when in actuality Sabrina had known the friend for twenty years.

Kelly also stated that her case study accurately reflected her situation. Corrections were made in the spelling of the names of the musical groups that her son enjoyed listening to.

Three readers were also utilized to review the transcripts and resulting case studies to determine the adequacy of the case study in reflecting the transcripts. The readers were first given copies of the transcripts and asked to identify those topics and issues that they felt would be important to include in the case study. They were

later given the case studies and were asked to determine if they adequately reflected what they had found in the transcripts. The readers were professional colleagues who had doctorate degrees and familiarity with qualitative research. Both Julie Maloney and Alison Boyer had previously conducted qualitative research. In each case no major corrections were made but some minor typographical errors were corrected and some clarification occurred. Following are quotes from the readers.

Julie Maloney (1996) who reviewed Sabrina's transcripts and case study stated, "I found that you drew out the themes from the transcripts very accurately in the case study. I like the way you organized the information and your headings make a lot of sense (personal communication)."

"I think what you've written here (case study-John) is an extremely accurate summation of the transcripts I read" (Alison Boyer, personal communication, 1996). Alison reviewed Kelly's transcripts and case study.

The transcripts and case study for Sue were reviewed by Eve Malo (1996). She stated, "The case study was congruent with the transcripts. For example, Sue talked a lot about loneliness and not having a social life in the transcripts. This was sensitively reflected in the case studies (personal communication)."

Triangulation of data was also utilized to establish trustworthiness. Methodological triangulation is the

utilization of more than one method to examine a problem (Patton, 1990). For this study I used both individual interviews and focus groups. Frey and Fontana (1993) list triangulation of individual interviews as one of the reasons for using focus groups, stating the "cross-referenced multiple opinions stemming from its [focus group] group nature lend methodological rigor to the one-on-one interpretive nature of field interviews and ethnographic reports" (p. 24). Focus groups can be used to balance the weaknesses found when only interviews are used. One advantage of focus groups is that they can produce data with little input from the researcher (Morgan, 1988). Therefore, they are less controlled by the researcher than individual interviewing. This appeared to be true in my study. In reviewing all the focus group transcripts I found that I spoke an average of 4.9% of the time. The focus group also allows a greater number of viewpoints to be heard thus stressing breadth while the individual interviews stress depth. The group interaction also acts as a springboard to cause material to be revealed that may not come out in interviews with single subjects (Morgan, 1988).

> Normally people are not in touch with or able to articulate their motivations, feelings, attitudes, and opinions. Many of the behaviors we might wish to understand are not matters of conscious importance to research participants. At the beginning of a focus group, such participants will not be immediately able to express all their feelings or motivations on a topic. As they hear others talk, however, they can easily identify the degree to which what they are hearing fits their situation. By comparing and

> contrasting, they can become more explicit about their own views. In addition, as they do express their own feelings and experiences they may find that answering questions from the moderator and other participants makes them aware of things that they had not thought about before . . . The interaction in focus groups often creates a cuing phenomenon that has the potential for extracting more information than other methods (Morgan and Krueger, 1993, p. 17)

Experience with Qualitative Research

To be effective the qualitative researcher must have a tolerance for ambiguity, sensitivity, and be a good communicator (Merriam, 1988). Merriam (1988) describes the good communicator as one who "empathizes with respondents, establishes rapport, asks good questions, and listens intently" (p. 39). Letting those reading the research know about the researcher's training and experience in these areas is an important way of establishing credibility when conducting qualitative research.

In relation to training, I have completed doctoral coursework in conducting qualitative research. In addition, I have participated in numerous workshops and have completed 15 credits of course work and practicums in social welfare which emphasized interviewing and communication techniques. I have also had several opportunities to gain experience in using these techniques with families. One of these was in a position as a Head Start disability coordinator which I held for two years. In this position I met with families to discuss their special need's children. I have continued to utilize these skills for the past three years in my position

with the Women's Resource Center where I facilitate a local ADHD support group and meet individually with parents who need additional support. There have been several other situations where I have facilitated groups, including facilitating meetings for one year between a tribal Head Start and non-tribal public school which we designed to address and reduce the conflicts that were present between the two groups.

I also conducted a pilot study on the impact of ADHD on one mother (Bullard, 1994) which utilized in-depth interviews and a general interview guide and resulted in a case study. Two in-depth, 2 hour interview sessions were conducted with Anne (pseudo name), a parent of a 12-year-old ADHD child. A major finding of the pilot study was that although Anne was using an extensive repertoire of coping strategies including medication for Eric, changes in expectations, a behavioral management program, personal stress reduction techniques, belonging to an ADHD support group, and receiving counseling that Anne still described the experience of raising an ADHD child as extremely stressful. Anne discussed the impact on her emotions as being especially difficult. She described strong feelings of guilt, exhaustion, stress, inadequacy, embarrassment, worry, and negative feelings about herself. Following the interviews the mother was asked for feedback regarding the process.

In summary, although I have limited experience conducting qualitative research, I have had numerous training opportunities and a variety of experiences utilizing communication skills such as open ended questioning, reflective listening, and facilitation skills. I feel that these skills plus my experience as a parent of ADHD children and specific knowledge about ADHD, will allow me to be empathetic, sensitive, and a good communicator.

Population Description and Sampling Procedure

The population for this study consisted of three mothers having ADHD children who participated in in-depth interviews and 11 additional families who participated in the focus groups. Two of the mothers who participated in the individual interviews also participated in the focus groups creating a total of 13 families participating in these groups.

Individual interviews were continued until the data being collected became redundant and the themes began to repeat themselves (Lincoln & Guba, 1985). The sample was chosen using purposeful sampling. While the purpose of random sampling is representativeness, the intent of purposeful sampling is "to select information-rich cases for in-depth study" (Patton, 1990, p. 182). Purposeful sampling can be accomplished through a variety of sampling strategies. The strategy I chose was critical case

sampling. Critical cases are those that can "make a point quite dramatically or are, for some reason, particularly important in the scheme of things" (Patton, 1990, p. 174). According to Patton, "critical case sampling permits logical generalization and maximum application of information to other cases because if it's true of this one case it's likely to be true of all other cases" (p. 182). Since this study examined the stress in ADHD families, critical case sampling meant that I would study families having ADHD children where stress was least likely to occur. Studies indicate that parent's stress is increased when children are preschoolers (Mash & Johnston, 1983) or adolescents (Pasley & Gecas, 1984), when children or mothers have other major disabilities (Anastopoulos, et al. 1992), and when families are experiencing major life changes (Holmes and Rahe, 1967). When children receive medication to alleviate the symptoms of ADHD they improve their behavior and compliance (Barkley, 1988, 1989; Barkley, Karlsson, Pollard, & Murphey, 1985; Barkley, Karlsson, Strelecki, & Murphey, 1984). Since child indicators are the greatest variable in accounting for the increased stress level in ADHD parents (Anastopoulos, et al. 1992; Baker, 1994; Mash & Johnston, 1983b) one would expect that therapeutic levels of medication would lower parental stress. Therefore, I used the following criteria in selecting cases:

1) Determination of ADHD by a physician, based upon information from a variety of sources including parent and teacher ratings, interviews, neurological exam, physical, child and family history.

2) A diagnosed child between the ages of six and twelve.

3) The use of medication to mitigate the symptoms of ADHD.

4) Diagnosis and treatment of the disorder with medication for at least two years.

5) The absence of any major life change within the family during the previous six months including death, long term hospitalization, or divorce.

6) Absence of obvious or known severe physical or emotional disabilities in the child or parents.

7) Volunteers living in three communities and surrounding areas in Southwestern Montana.

It was difficult to locate families for this study because ADHD families are not readily identifiable. Unlike children with other disabilities, ADHD children do not look different physically from other children. Therefore, unless the parents or children choose to share this information, schools or even neighbors may not know the diagnosis. While we can estimate the number of families in a community based on the predicted percentages of children who have ADHD, lists of these families do not exist. For this reason,

participants for this study were selected through referrals from ADHD support group leaders, parenting class instructors, other participants, and self referrals. Those referred were contacted by telephone using a screener questionnaire as described by Zeller (1993) (see Appendix B). The purpose of the screener questionnaire was twofold. First, to select participants who fit the research criteria. Secondly, the screener questionnaire allowed the participants to begin to think about the topic (Zeller, 1993). This was especially important for those participating in just the focus groups, since I only interviewed them once.

I first contacted parents to participate in the individual interviews. One of these mothers was referred through a support group facilitator, another through a parenting class instructor, and the third had heard that I was doing the research and volunteered. Each of the mothers was initially contacted by phone. I used the screener questionnaire to see if they met the criteria for the study. These initial phone calls lasted 1 hour to 1 hour and 15 minutes. Each of the mothers met the criteria and agreed to participate. Although I was able to explain the purpose of the study, the time commitment required, and to complete the screener questionnaire in approximately 15 minutes, the mothers were eager to share information about their children and began to discuss this during the initial contact. In

Sabrina's case I also was invited to her home to have supper and to further discuss the study. Although the initial phone conversations with each of the mothers and the visit with Sabrina were not recorded or transcribed I feel that this time did assist in building a relationship with the mothers.

Each of the mothers lives in a different community in Southwestern Montana. Sabrina is a 43-year-old single mother who lives in a small rural community (population 150). Her son, Jim, is ten and has ADHD and a learning disability. Sabrina is a head teacher at a local elementary school.

Sue is currently pursuing a doctorate degree. She is 42, is married and lives in a community near one of Montana's major population centers. Her ADHD son, Chris is 12. She also has two other children who no longer live at home. Both Sue and her older daughter have been diagnosed as having attention deficit disorder (ADD).

Kelly is 32 and is also married. She, her husband and three children live on a ranch. She is a student and commutes two hours each day to attend school. John, her ADHD son, is six and is the middle child. Kelly suspects that her husband also has ADHD although no such diagnosis has been made by a physician.

After identifying parents to participate in the individual interviews, I contacted ADHD support group

leaders and others to locate parents to participate in the focus groups. Below is a table which shows the results of this search.

Table 3

Parents contacted to participate in focus groups

Group	Number of parents contacted	Source of referrals	Number of parents eligible	Number of parents attending	Reason for not attending
Focus Group 1	7	6 support group 1 other	6	4	1 emergency 1 time conflict
Focus Group 2	14	12 support group 2 other	8	6	2 time conflict
Focus Group 3	7	5 support group 2 other	5	3	1 no show 1 time conflict

The "other" category included those referred by parenting class instructors, through self referral, or through referral by a parent who was contacted to participate in the interviews.

Three focus groups were held in three communities in Southwestern Montana. These focus groups were numbered and the communities were not identified to protect the anonymity of those participating. Below are tables for each of the focus groups which gives data about those who participated. If a space is left blank, it is because the data were not available.

Table 4

Participant Characteristics in Focus Group 1

Participant	Age	Educational level	Children's gender	Children's age	Children diagnosed ADHD or ADD
Married father	43	Bachelors degree	Daughter	19	yes
			Son	12	yes
			Daughter	10	no
			Son	6	yes
			Son	4	no
Married mother	33	College,no degree	Daughter	13	no
			Daughter	11	no
			Son	9	yes
Divorced father	32	College, no degree	Daughter	12	no
			Son	10	yes
			Daughter	9	yes
			Daughter	6	no
Married mother*	31	College, no degree	Daughter	8	no
			Son	6	yes
			Daughter	4	no

* also participated in individual interviews

Table 5

Participant Characteristics in Focus Group 2

Participant	Age	Educational level	Children's gender	Children's age	Children diagnosed ADHD or ADD
Married mother*	42	Master's degree	Son	20	no
			Daughter	18	yes
			Son	12	yes
Married mother	50	Doctorate	Son	8	yes
Married mother	36	High school	Son	7	yes
			Daughter	4	no
Divorced mother	26	College, no degree	Son	8	yes
Married mother	39	Bachelor's degree	Son	8	yes
			Daughter	6	no
Married mother	48	Bachelor's degree	Daughter	15	no
			Son	12	yes

* also participated in individual interviews

Table 6

Participant Characteristics in Focus Group 3

Participant	Age	Educational level	Children's gender	Children's age	Children diagnosed ADHD or ADD
Married mother			Daughter	17	no
			Daughter	11	yes
			Son	10	no
Married mother	38	Bachelor's degree	Daughter	12	yes
			Son	9	no
			Daughter	5	yes
Married mother			Son	19	no
			Son	12	yes
			Daughter	10	no

In summary, using critical case sampling, three families were chosen to participate in in-depth interviews and an additional 11 families participated only in the focus groups. These families were located through referrals from support group leaders, parenting class instructors, self referrals and referrals from other participants. I used screener questionnaires to determine whether participants met the sampling criteria.

Data Collection

Interviews

I collected data through multiple in-depth interviews with three families utilizing a general interview guide approach. Information was also collected through three

focus groups, each consisting of three to six families using a nondirective method with limited questions and probes.

The interview is a technique which is used to "gather descriptive data in the subjects' own words so that the researcher can develop insights on how subjects interpret some piece of the world" (Bogdan & Biklen, 1992, p. 96). Through interviewing one can learn about a person's thoughts, perceptions, feelings, and about private lives and relationships. This led Weiss (1994) to say, "most of the significant events of people's lives can become known to others only through interviewing" (p. 2). Since the purpose of this study was to gain perspectives about relationships, interviewing was the logical methodological choice.

I conducted multiple interviews with each participant. The multiple interviews were crucial because the increasing contact helped to build trust and confidence thereby allowing more information to be shared. In addition, the subjects had the intervening time between interviews to reflect upon their experiences, note new incidents, and allow new memories to surface (Weiss, 1994). I followed Weiss's suggestion of planning for a minimum of three interviews. In his research he found a significant increase in new information in the first three interviews, with diminishing returns in subsequent interviews. As a final way of determining when to end the interviewing, I used Lincoln and Guba's (1985) recommendation that when the data

being gathered became redundant and the themes and patterns began repeating themselves I ended the data collection. In addition to the initial phone contacts with each of the mothers and the personal visit with Sabrina, I conducted personal interviews with each of the mothers three times. In addition, I conducted an additional phone interview with Sue. I met a final time with each mother to review the case studies. In Kelly's and Sue's cases these were personal meetings. Sabrina had moved out of the state by the completion of the study so we had our final meeting over the phone.

At the end of the initial phone call the first interview was scheduled around the convenience of the participant. I phoned again before the initial interview to verify the time and date and to mention the general topics the interview would cover. This pattern of establishing the next interview date and confirming before the interview was followed for each of the subsequent interviews. The mothers generally came to the interview having thought about the topics and with information that they wished to share. The interviews began with them sharing this information. The mothers also often came with anecdotes that they wished to relate. A typical example of this was when Kelly came to her interview and started with, "I had a terrible night last night and then I remembered that today was my interview and I wanted to make sure I shared what had happened with you."

The interviews were also scheduled in the participants choice of setting. Kelly's interviews were each held in my office with the exception of the final meeting which was held at a restaurant. Sue's interviews were held either in her office or her home, with the final meeting at a restaurant. The interviews with Sabrina were held in her home or in my home and generally involved sharing a meal together.

The interview data were collected during 1 hour and 30 minutes to 2 hour interview sessions using a general interview guide approach (see Appendix C). The general interview guide listed the topics and issues to be covered but allowed me to vary the sequence and wording of these during the interview to allow the interview to flow in a more conversational way and to be more natural and relevant to the subject (Patton, 1990). As Ely et al. (1991) described, as the interviews progressed and data was analyzed, new questions evolved (Ely et al., 1991). These questions generally involved further clarification of topics raised by the participant. For example, Sabrina discussed extensively the small rural community in which she lived and how it impacted her ability to cope with her son's ADHD. Other topics that she raised that I had not originally included in the questions were the impact of her son's ADHD upon her job and upon her decision to move to a new community.

Prior to its use in this study the instrument had been used in a pilot study. Several people reviewed the instrument, including parents of ADHD children and students from a variety of disciplines who were conducting qualitative research. The mother participating in the pilot study was also asked for feedback on the instrument resulting in further changes. Some of these changes were the addition of questions regarding having parents rate on a scale of 1 - 10 how stressful they feel parenting their ADHD child is and rating on a scale of 1 - 10 how well they feel they are coping. The instrument underwent further changes when it was reviewed by the six members of my dissertation committee.

In conducting interviews the researcher must establish rapport and a climate of neutrality (Patton, 1990). Researchers display neutrality in the way that questions are worded and also in the verbal and nonverbal responses by the interviewer to the subject's answers. Rapport is the relationship with the person being interviewed. "Rapport is built on the ability to convey empathy and understanding without judgment" (Patton, p. 317). To build rapport and convey empathy, I disclosed the fact that I am a parent of ADHD children.

With permission from the subjects, the interviews were audiotaped. As a way of safeguarding the subject's rights, I informed them of their ability to terminate the taping and

the interview at any time. However, no participant exercised this option. Informed consent (see Appendix D) was obtained for the use of data collected through the interviews. The informed consent form was approved by the Montana State University Human Subjects committee. In all cases the information obtained was kept confidential. One way this was accomplished was to change the names of the participants and their families and not disclose the locations where they live when reporting the information obtained.

Focus Groups

For this research project, I held three focus groups consisting of three to six parents of ADHD children. These groups were held for one and one half to two hours and took place in three communities in Southwestern Montana.

A focus group is a group of peers brought together to share diverse viewpoints and thoughts regarding a topic which is selected by the researcher (Morgan, 1988). It is similar to a group discussion in that the researcher supplies the topic, but it is the interaction between the group that causes the topic to continue (Morgan, 1988).

Focus groups have their roots in sociology, with the first published focus group being conducted in 1946 by Robert Merton to examine wartime propaganda and how persuasive it was (Morgan, 1988). While focus groups have been used most extensively in marketing research (Morgan,

1988), there has been a recent resurgence in their use in social sciences (Knodel, 1993).

As described previously, I chose to use focus groups as a research method for several reasons. These included the ability to triangulate themes and patterns, provide balance to the interviews, and to raise the consciousness level of the participants.

Focus group interviews were conducted after the completion of the individual interviews. My initial plans were to have those mothers participating in the individual interviews also participate in the focus groups as a way to raise their feelings and thoughts to a conscious level thus providing new information. Two of the mothers did participate in the focus groups. However, they did not share any new information in the group interviews. I had continued the in-depth interviews until the material being shared became redundant. The fact that no new information surfaced may have been a verification that this had occurred.

A moderator generally leads focus groups. There is disagreement in the field about the characteristics of this role. While all agree that the moderator must have good communication and facilitation skills and that the moderator is one of the keys to the success of the group, whether this should be someone that is outside the research project is debatable. Krueger (1993) states that having someone that

is too close to the project can jeopardize the project by narrowing the arguments into preconceived categories and through the researcher being perceived by the participants as holding a particular position on an issue. However, Morgan and Krueger (1993) state that in many cases it is preferable to have a member of the research team facilitate the focus group. They state that this is particularly true when participants are members of distinctive cultural groups where the appropriate degree of sensitivity will be more important than professional credentials. Zeller (1993) further argues that when one is discussing sensitive issues capitalizing on self disclosure is crucial. Self disclosure is considered to be information that participants would generally not share with just anyone. The goal in dealing with sensitive issues is to increase the upper limits of appropriate disclosure. The moderator, who is often a stranger to the participants, wants participants to feel secure in sharing sensitive, personal information. If the focus group is going to be effective, the researcher must establish a great deal of interpersonal rapport within the first 15 - 30 minutes. Zeller states that this can be accomplished through a relatively high level of self disclosure on the part of the moderator. Since the goal of this research was the sharing of sensitive information regarding parenting an ADHD child, it appeared to be beneficial for the facilitator to have experienced raising

an ADHD child. In this way self disclosure could be used as an effective means in building group rapport and raising the level of self disclosure. Since I am a parent of ADHD children who has received training in facilitation I was the moderator for the focus groups. To increase reliability I moderated each of the groups (Klein, 1989).

The role of moderator can be very nondirective with very limited questions and probes to very directive utilizing a structured, ordered set of questions. A low level of interviewer participation is especially suitable in gaining new insights from participants or in determining what the participants view as key points. A high degree of involvement on the part of the facilitator is most appropriate if one is comparing groups or providing answers to specific research questions (Morgan, 1988). Since the goal of this research was to gain new insights and also to use the focus groups as a means of triangulation by reducing the amount of researcher control, a nondirective method with limited questions and probes was utilized (see Appendix E). The nondirective method allowed the participants to interact with each other, not just the researcher, as was the case in the individual interviews. It also allowed me to see what information emerged from the group itself. As Morgan (1988) stated, this approach led to more emphasis on the participant's points of view. However, the less directive approach also made it impossible to quantitatively determine

participants' viewpoints. For this reason, the words "few," "several," or "most," are used in describing the results rather than a specific count.

In utilizing a nondirective approach, I developed a discussion guide, which consisted of open-ended questions and a few probes, following Morgan's (1988) recommendation that topics be limited to two to five areas. Keeping the questions open-ended, and reducing the amount of questions asked, allowed me to follow useful trains of thought that I had not previously anticipated (Knodel, 1993). For example, focus group one discussed extensively the difficulty with their children's destructiveness. I had not previously anticipated that this would be a major topic.

The initial questions were left deliberately vague in the focus groups. In qualitative research the researcher tries to avoid making assumptions. Even though previous studies had indicated high levels of stress in families with ADHD children, the purpose of the focus group was not to put my preconceived notions in the participant's minds (Patton, 1990). I had predetermined that if, in the initial round of sharing, stressful experiences were not revealed then further probes in this direction would not be utilized. However, in each of the focus groups stressful experiences were shared by each of the parents.

The study included three to six participants in each focus group. Although small groups are more sensitive to

dynamics than large groups and provide input from fewer people, this number allowed a maximum amount of sharing by each participant and the smaller numbers assisted in creating the rapport needed in dealing with sensitive issues (Morgan, 1988).

The focus groups were held in a neutral, comfortable, convenient, non-threatening environment. As parents entered they were offered refreshments and were asked to complete a permission form (see Appendix F) and questionnaire (see Appendix G). This was followed by self introductions where participants gave their name, briefly described their ADHD child or children, and described one event or episode and the emotion that they felt at the time this occurred. This allowed each participant to speak and also provided some basic general information. In addition, this allowed everyone to get on record with their experiences (Morgan, 1988, p. 58). In following recommendations from Zeller (1993) I began and disclosed that I am a parent of ADHD children and shared a recent situation with my children. After the introductions I briefly paraphrased the experiences that had been identified and asked for additional information. Reflection and probes were utilized as needed to sum up material, fully understand what was said, and to explore areas that had not yet been addressed.

Most of the questions that I asked were regarding topics that were first raised by the participants. However, near the end of each focus group I read a quotation from one of the mothers in the individual interviews regarding what she termed as "disassociation.". I then asked if any other parents had experienced this. Since this was a method of coping which two of the mothers in the individual interviews had mentioned, I felt that this was an area that might be worthwhile to explore. In addition, this coping mechanism had not been described until several hours of interviewing had occurred so I did not expect that it might surface in the focus group unless a question regarding this method of coping was asked.

At the conclusion of the focus group each participant was asked to make a closing statement. This allowed participants the opportunity to make any final contributions, including those that may not have been previously shared (Morgan, 1988).

In conclusion, interviews and focus groups were utilized to complement each other. The information received from focus groups was a means of triangulating themes and patterns found in the individual interviews. Also, while the individual interviews provided in-depth information through the dialogue between myself and the participants, the focus groups balanced the individual interviews by decreasing my input and allowing more breadth to the

project. Finally, the focus groups were used to raise the consciousness level of those involved.

Data Analysis

Interviews

With permission from the participants all the interviews were taped and transcribed. Analysis of the interviews was ongoing with collection of future data being influenced by what was found in previous interviews. Following each interview transcriptions were made and the material was examined and coded with emerging categories before the next interview. Ongoing participant checks were utilized to clarify the data, the patterns discovered, and the emerging conclusions. This included reading sections of previous transcripts to the participants so that they could clarify or expand upon their thoughts.

Data from each participant was then consolidated and organized topically into categories. Following recommendations from Lincoln and Guba (1985) categories were developed that could account for the majority of data with less than 5% to 7% percent of the data not clearly fitting into a category. Categories were also examined for "internal homogeneity" or how well the information related to other pieces of information within the same category and "external heterogeneity" or how well the categories prevented overlap with other categories (Guba, 1978).

Merriam (1988) states that case studies may be written at this point as descriptions of what was found or the researcher also may continue to analyze and interpret the data looking for overriding conceptual categories, patterns, and themes. I used both approaches, first looking for categories within each case and writing these as a descriptive case study and then examining overriding conceptual categories across case studies resulting in a summary of case studies. Included in this summary were categories that emerged in either two or generally all three individual case studies.

Focus Groups

With permission from the participants, the focus group sessions were also audiotaped and transcribed. Morgan (1988) states that audiotaping is essential to capture the dialogue that occurs. Although videotapes provide nonverbal data as well, this was not included due to the intrusive nature and the difficulty in obtaining high quality tapes (Morgan, 1988). In addition, to achieve quality, videotapes require an additional person to run the camera. Additional people who are not involved in the focus group can jeopardize quality (Krueger, 1993).

As with the case studies the data from the focus groups were consolidated and categorized. There was no attempt to use the same categories as were used in the individual interviews although due to the similar data between both

methods this frequently occurred. A summary of the focus groups was then written. Quotations were chosen that were representative of the group and that were most clearly articulated. As recommended by Weiss (1994) when participants used conversation spacers such as "uh" they were not included in the quotations. Since the two mothers who participated in both the individual interviews and focus groups revealed no new information in the focus groups and the information they had previously supplied had been included in the case studies, quotes from these mothers were not used in the focus group summary. Also, if contradictory information was given, even by one person, this was noted in the summary.

The final step in data analysis was to examine the findings of the focus groups and the case studies for the emergence of regularities. Information was included in the summary which was described in both the individual interviews and the focus groups. As the categories were re-examined this final time, overriding themes were identified and a final summary was written.

CHAPTER 3

DATA

This section will contain data which was collected through in-depth interviews with three mothers resulting in three case studies, a summary of the case studies, and a summary from the three focus groups.

Kelly, Sue, and Sabrina are three mothers who have ADHD children. Each mother was involved in at least three, 1 to 2 hour interview sessions. In addition, after the case study was written I again met with each mother to review the case studies. These were personal meetings with Kelly and Sue. Sabrina had moved out of state and therefore I had a meeting with her by telephone. As a result of these participant checks minor details were clarified. For example, Sue clarified that her son had broken his knuckle rather than his finger.

Participant checks were also used as an ongoing process. With permission from the participants, interviews were taped. Following each interview transcriptions were made and the material was examined and coded with emerging categories before the next interview. Participants were asked to clarify data, the patterns that were emerging, and the emerging conclusions.

Interviews were arranged around the convenience of the mother in her choice of setting. The mothers were contacted

before each interview to confirm the date and time and to mention the topics that we would be covering. This resulted in the mothers generally coming to the interviews with information that they wished to share and this then became the starting point of the interview.

The transcripts and case studies were each reviewed by an objective reader. This resulted in correction of minor typographical errors as well as some clarification. Each of the readers stated that the case studies accurately reflected the transcripts. An entire set of transcripts was also reviewed by a reader to determine the neutrality of my questions and responses. In a review of 55 single spaced pages, she found that I had asked questions or made responses 169 times. Only one of these responses was non-neutral (see Appendix A).

Kelly's Case Study

Kelly is a 31-year-old college student majoring in education. She and her husband, Bob, live with their three children on a family ranch which is five miles from a small rural town in southwestern Montana. Kelly describes her husband as a "workaholic" who spends long hours each day working on the ranch. She states, "We don't set plates for him at the table because he's never there." She also says, "He doesn't take any days off, except for on Christmas he

might take most of the day off." This has resulted in Kelly shouldering most of the parenting burden.

Their oldest daughter, Cindy, is eight and in second grade. She plays baseball and is on the swimming team. John, their middle child who is six has attention deficit hyperactivity disorder (ADHD). He has not started school yet. Their youngest daughter, Tanya is four. She attends the day care on campus along with John. For the past two years Kelly and her two children have commuted two hours per day, five days a week to attend college and day care.

John's Behavior

Kelly describes John as a "bright, happy, fun little boy," who "loves to manipulate things." For example, they had an old John Deere tractor which was missing a seat and steering wheel which he rebuilt. He also likes to create with boxes, blocks, and Legos and fill his bedroom with projects. "He loves to create them and he loves to admire them, because he's very proud of his work." John also enjoys various kinds of music. "He listens to Vivaldi, African singers, and Silly Wizard which is an Irish group. He's very diversified musically." While listening to music, he loves to rock on a large dinosaur made by his grandfather. But John is also "busy" and "not easy to handle." In describing the risk taking behavior he exhibited before beginning medication, Kelly says,

> He would jump from tables to couches that were five and six feet apart. Once I had to take him to the doctor's office to make sure he didn't have a concussion or something because he had hit the corner of the table.
>
> He would climb trees as a very small child not even out of diapers. I had to watch him like a hawk. He would take hoes and chase after people. Even before he could walk, I found him sitting on the middle of the kitchen table, he must have climbed up on chairs. A lot of kids will do this but he did them constantly.

It was also difficult getting John to sleep. "He couldn't settle down. We had a lot of throwing the toys at walls and such. Every night and every nap time was very difficult." He would finally fall asleep at nine or ten at night. In addition to dealing with the behavior, Kelly said this was hard because, "I've always been one who likes to have my kids in bed at least a couple hours before I go to bed, because I need time. I need adult time and I wanted time to sit down and relax."

When describing other behaviors that John exhibited, Kelly said, "I was constantly dealing with temper tantrums, I couldn't let him out of my sight because he might do something horrid and hurt himself. He was constantly biting her [sister], hitting her in frustration." The tantrums were especially difficult to deal with.

> He would scream constantly, hit, kick, throw things. The walls in the room he was in had marks everywhere. He would dump every toy and throw every toy, hit things, just very destructive. These would go on for 45 minutes to an hour, to the point where finally he would stop and say, "Mommy my head hurts." He'd screamed so hard and yet he didn't want me to let him down and yet he fought me . . . . He had no inkling that there was a consequence that if you threw a toy against

> the wall it might break, it could be his most favorite toy in the whole world.

Kelly described how she dealt with the tantrums.

> I remember rocking him when he was screaming for an hour and a half and singing quietly to him or I would tell him a story. I would just talk to him about how a little boy named John would play in a sand box and he would build roads and I would speak softly trying to get his attention. I would pick him up and hold him or I would talk or sing very quietly to him, songs he likes or songs where I would use his name because he was so out of control.

It was not just the length or severity of the tantrums that were difficult but also that their occurrence was and still is unpredictable.

> Things are by the moment. Ten minutes from now they might be totally out of control. Where right now they are playing quietly, no fighting, nothing is going on. Or it might be two minutes from now. They are going to have a big temper tantrum but you see nothing coming up.

"Little things would set him off, like I have to go and take a nap or I can't have that one little toy that I wanted right now, I have to wait - so it wasn't big huge things."

In discussing her feelings Kelly said,

> I felt like it was my fault for a long time. I'm obviously not doing something right here. I tried everything I could. I wondered what was wrong, with the rocking I was thinking autism and yet I didn't see that as a constant thing. I guess I really wondered if there was something wrong with me for a long time.
>
> I felt like a failure. It doesn't matter what I do this child misbehaves. It doesn't matter how patient you are, how loving you are. They do the same thing over and over again. Every time you're around other people they make it clear that they think you're not disciplining appropriately.

Then Kelly's sister read an article about ADHD and urged her to take him to a doctor. John was three and one half at this time. Kelly took him to a pediatrician in a nearby town and sat "bawling in his office saying I can't take this anymore.". She said, "I've never broken down in front of someone else like that in my life. I just went in and I couldn't stop crying." He diagnosed ADHD through a comprehensive evaluation which included interviews, checklists, family and developmental history, a physical, and a neurological exam. Regarding the diagnosis Kelly said, "It was a relief to know it wasn't me because I really felt like I was going crazy." He also recommended another doctor for a second opinion. Bob and Kelly then took John to a pediatrician specializing in behavioral disorders who confirmed the diagnosis of ADHD. As they were being interviewed about family history and the doctor shared information about the symptoms of ADHD, Bob said "that is exactly what I went through as a child." Kelly believes that Bob still displays ADHD symptoms. She states, "Unfortunately he thinks that it is gone, which has been hard. He doesn't recognize the fact that it's not something that just picks up and goes away."

Since being diagnosed John has been on Dexedrine which he takes three times a day. The decision to put John on medication was very difficult. When Kelly was discussing this, she said,

> I think part of the reason I was a little nervous is because I grew up with a dad who is a physician. He's very conservative and so drugs are used medically only when you need them. You aren't to take them because you feel a little sick. And so when I found out what they treated these kids with and they said what this is on the street, compared to what it is when you buy it as a prescription, all of a sudden little bells went off. Oh my goodness, I'm giving this to my kid. Because we've always been taught that you don't touch these drugs.

She overcame her reluctance by educating herself and changing her beliefs. "I had to educate myself into thinking, this is like a diabetic, he needs this, and that helped." The decision to medicate was reinforced when Kelly witnessed a huge change in John's behavior and development after medication began.

> It was a drastic change, in two weeks he was diaper free . . . His speech all of a sudden started coming very quickly and things were just instantaneous as far as behavior changes. They weren't perfect because he was doing all these things for so long. But they were so much better. So there was a big change.

John currently takes medication three times a day, including weekends and holidays. Medication has made a big difference but it has not been a miracle cure. Kelly says, "He does pretty well now, he's not perfect, a long way from perfect, tolerable." "Medication did not solve the problem completely. You need behavior management." For example, John still has tantrums which occur at unpredictable times but, with medication they are much more manageable.

> Fortunately those [temper tantrums] don't happen very often now and if they do, generally I can put him in timeout for a length of time or put him in his room and say you need to stay in your room until you're ready to

> talk to me. They go various lengths but they are much more tolerable and normal.

In describing a recent tantrum, Kelly says,

> He started throwing his bedding out the door and his favorite bunny. He would throw things that would make me angry, not with the intention of breaking anything. He does love his toys, although he'll still throw those too occasionally but not like he used to.

However, their daily car rides can still be troublesome.

> It's like he's got all this energy and he needs to expend it. So hitting sister with a coat or whatever is within reach is what he might do . . . Or to get their attention he might wing this little toy at them.

John can also still be difficult for others to handle.

> The church school teacher told me that he was being mean and he had kicked such and so for whatever reason and wouldn't mind worth a hoot. He would completely ignore everyone else no matter what they were saying to him and he would giggle and laugh and throw himself on the floor, roll around. He had no concept that he had to actually listen to this person.

Kelly started volunteering in the class to help alleviate this problem. In describing their experience with swimming lessons, Kelly said,

> He wasn't one you could put into a group of kids. First of all he didn't pay any attention to the teacher most of the time, and second he was a kid that had no fear. He would drop off the side and go under and if the teacher is not Johnny on the spot, it could scare him bad enough to be a problem or something could happen.

So Kelly paid for private lessons.

> He did ok but he still wasn't listening to her most of the time. It was frustrating for her because she's used to having a group that does this, this, and this. She would just say, "I think he has had enough today or whatever" which meant that I spent a lot of money for very little time.

Kelly said that she ended up teaching John to swim.

It also is very trying if he doesn't have medication in his system. Kelly describes some examples where she questioned whether he had received his medication. These both occurred during the period of time that we were interviewing.

> I wondered if I should ask the day care if he had his medication in the afternoon because he was absolutely off the rafters all the way home. I mean he was bopping in his seat. He was flinging things. He was angry. He was mad because I hadn't packed two sandwiches and I only packed one and his bag of pretzels. He was kicking his shoes and flipping them around all the way home. When he got home it just continued along this line. I mean he was bopping around at the dinner table. He'd made such a mess with his taco. More of the taco was on the floor than in him. He had a bath and went to bed and he was flinging things around his room. It was like he wasn't even taking medication.
>
> Last night was horrible. He wasn't horrible in the sense that he was doing horrible things. He just couldn't sit still. I took them to a restaurant down town, which is like a pizza parlor. He wouldn't sit still for the life of me. He kept getting up and bopping up and bopping down and this and that and the other thing. He didn't listen. Then we went to get our hair cut. He just kept bopping around, taking the doll from his sister. He just could not even for a second sit in that chair. I kept thinking, boy did he take his medicine. But it was late, so it had worn off already.

Impact on Siblings

Kelly states that when you have a child with ADHD, "you have to adjust everything in your life and unfortunately the other kids in the family have to be put on the back burners." She said,

> I think my oldest has been impacted a great deal because from the minute he was born not only did she have another sibling to share me with where before

> she'd had me all to herself. But, now she had this brother that not only took me but took me so much.

During the interviews she gave some specific examples of this. One of these was an incident where Cindy wanted her mother to read her a story. However, Kelly had just placed John in the car because he was "out of control" and was standing in the doorway so she could watch her younger daughter get her hair cut while also watching John.

> Cindy said, "Mom would you just sit down and read this to me." I said, "You know I would love to but I have to watch John and I'm just too tired. This weekend we will sit down and read the book." I felt guilty but it was the only way I could do it. She was so understanding about it which probably is because she's had to do it so many times.

> She's not had as much attention as she's probably needed . . . He demands so much time that the other siblings get pushed aside when you're dealing with his temper tantrums which might go on for an hour. They have to go do something. They can't talk to you, can't bother you because you're trying to contain this child.

Kelly also described how the amount of attention that John demands affects even her mother's relationship with her other children.

> My mom in some ways, I don't know if you would really say favors him. He demands so much more attention consequently it kind of looks like that. Once my brother commented that she always tells them what John is doing but it doesn't seem like she really tells him what the girls are doing. "Well it's because he's doing so many wild things." My brother said, "Yea, he's interesting and exciting to watch isn't he."

Cindy and Tanya are also impacted by behavior that John directs at them. "To have someone who is constantly demanding attention and constantly poking and prodding and

throwing things off and on, I'm sure it's going to have an effect on them long term, too."

In addition, they must deal with Kelly's reactions when she is feeling pressured. When Kelly and I discussed indicators that she was feeling stressed she stated that one way this was displayed was through, "Impatience, impatience with my oldest when she had done nothing to cause it. She might do some little minor infraction and I would come unglued."

Kelly also described how her emotions would sometimes impact her other children. She related one incident where John was "out of control and I couldn't deal with him in a patient positive way." So she placed him in his room and shut the door. She then sat on the floor outside the door and cried. Cindy came and comforted her. Kelly said, in recalling this incident, "That was hard for me and it was also hard for my other child. Of course they want to come and cuddle with you because they don't know what's wrong with mommy."

Impact on Kelly

Kelly says that every area of her life has been rearranged to accommodate John. "My life has changed so dramatically. I don't know what it would be like - [to not have an ADHD child]. So many things do center around making sure John doesn't have a problem." She describes the need to be vigilant.

> You just have to program yourself to be on a constant vigil, to watch what's going on. I've had so many people who do not know what his problem is and don't understand how carefully I watch him when we go places that maybe have a canal running by their house or whatever. They say, "Just let him go play." They don't understand what can happen. Why I am constantly having to say, "Ok let me see where they are. What are they doing?" It makes a difference. Your whole life is rearranged for this child. It has a big impact on everything you do.

Both preventing problems and dealing with them impact the time she has to spend with her other children and herself. Having friends over is also impacted. She says,

> I hesitate to have them over if I think it might be a problem. I don't need criticism. I have had friends that I know disapprove. They don't really say anything but you kind of get the gist that they don't think your method of discipline is appropriate and so consequently you don't tend to invite them over much, because you know you're going to have to do something while they are there. That's just standard procedure. So it [ADHD] does affect friendships.

It also impacted her ability to go places because it was embarrassing to take him but also difficult to leave him with a sitter.

> I got so that I just didn't want to go a lot of places because it was too difficult. It was embarrassing to go and have to constantly deal with this child . . . I didn't feel comfortable leaving him with anyone but my parents. They were the only ones I felt knew him well enough and knew how to handle him and knew how closely they needed to watch him. That was hard because I felt a little bit like a prisoner at times.

Now that John is on medication she can occasionally leave him. But she will make separate child care arrangements for the girls. "It has an impact on when I go. I don't leave him with babysitters very often. If I do, it's for a very

short time and it's by himself because that seems to work best."

In spite of all the other difficulties, Kelly states that the hardest part about dealing with ADHD is how it makes you feel. During the interviews she described many of these feelings:

The feeling of helplessness,

> When I try really hard to use time out or consequences and try to give choices and when none of those things work I feel so helpless. There are so many times that you feel helpless. You feel like you have no control, you're never going to have control again, nothing works. It's really difficult because there are so many things in your life that happen but you have a certain amount of control or you can fix them or you can deal with them and make them better. This you can't sometimes. It's not going to happen.

The feeling of frustration,

> It can be too demanding. This is a terrible thing to say but I finally understood how some people actually hit their children in anger. Because it is extremely frustrating. It's hard to curb that initial response. But, I've really tried hard to learn not to do that. It's not easy.

The feeling of stress,

> Sometimes there is this tremendous energy inside me that just wants to break out. I don't know really how to explain it but I feel very tight and coiled inside and I just know that I'm going to blow. It makes me a little bit sick to my stomach when I get that stressed.

The feeling of depression,

> There were lots and lots of times that I felt very, very stressed and depressed. Sitting down and having bouts of crying was not unusual. I don't have it too much anymore but I do get a big break now [Kelly attends college full time].

The damage to self-esteem,

Kelly reported that the pediatrician had told her that she needed to get an hour away by herself every day.

> I think it was also because he knew I was in the danger zone of going a little bit nutty. I felt so much like a failure and he threw a rope to me and I grabbed it and up I went.

The worry about how others will react to John,

Kelly said that one of the reasons that she commutes each day with the children rather than having them cared for in the town near the ranch, is so that John could be in a child care "that knew about his problem." She says that, "I worry about him being criticized and knocked down, because he is not easy." This concern has impacted her ability to leave him in the care of others.

> I couldn't leave him with a sitter. I worried, I worried about the sitter hurting him in frustration. Not that I ever had sitters that I worried would do that. But this is not a normal thing. You don't know what a sitter would do. Or if they would watch him carefully enough.

She also expressed concern about John starting school next year and is looking into a variety of options. She would like a teacher who has experience working with ADHD children, has a small class size, and who will "handle him in a positive way." But, she must also consider the logistics of transportation and after school child care. Cindy attends the school which is closest to their home. Kelly said that when Cindy started school she did not have as many concerns.

Impact on Other Family Relations

Bob's brother and his family's home are one quarter mile down the road and his mother's residence is one and one half miles. They all live and work on the family ranch. Kelly says that "the people who have made it harder for me [to cope with ADHD] have been my husband's family." She said that Bob's brother's children are "little robots that do everything just perfectly on command and if they don't then there is corporal punishment that can take care of these things." She said, "I would have trouble with this [corporal punishment] for any child, but especially with John." This has an impact on both her willingness to spend time with her husband's family and her ability to enjoy the time they do spend together.

> Where they are so critical of how I deal with my kids it does make it very hard. I do cope differently and I get much more frustrated than I normally would. Because if they are around it's almost like I feel like I'm being tested to see if my kids are going to behave. If I have to discipline them or talk to them about something how are they going to react? Are they going to mind me and stop whatever they are doing? So it's stressful. I try to avoid being around them because of that.

She also feels that Bob treats the children differently when his family is around.

> Bob gets very tense and I notice that he will be much more harsh with the kids when his family is around . . . It's like we are in a little movie that we are being graded on.

They have not told Bob's family that John was diagnosed with ADHD or that he is on medication. Kelly said that this is

because of their attitude about the way she disciplines.

> That had a big influence on whether I wanted to tell her [mother-in-law] about this. Because my feeling was, I don't think they would agree with us on the medication. I think they would just say, "Oh well you just need to be more firm with him."

Impact on Kelly's Marriage

Kelly discussed her marriage many times throughout the interviews. Kelly states that she and her husband disagree on how the children should be handled. She says that she doesn't think they would have too much of a problem if they just had the girls because there would be less disciplining.

> He's [Bob] a stress when he walks in the door because I know if the kids misbehave he's not going to deal with it in a positive, patient way. He is unable to do that. It's been a big problem. Our marriage is not good because of it.

> He will spank them. He doesn't do it to the point that I think he's going to injure them. But, that doesn't mean it doesn't hurt them. It's not like he's doing it constantly. There are people all over that spank their kids now. It's an accepted practice still to a certain point. So, I don't think they consider that child abuse. But, I have trouble not seeing it that way.

> He wants to do the quickest thing, the easiest thing for him to do. Of course, he's frustrated and angry and this helps release his anger. He doesn't look at it the same way that I do. I just figure that we need to try and exhaust all our other options before you do that. It's hard for him because his family believes that way and he's around them more than us [Kelly and her children].

She also feels that Bob treats John differently than the girls.

> He is more tolerant with the girls. I wonder if sometimes it's because he knows that John's going to do things so much of the time, that he gets very impatient

> with him . . . He tries, I think he does try and he's been trying harder because he knows that he needs to be careful because John is really an easy child to get angry with.

Kelly also worries about how Bob will handle John, saying, "I worry about how he'll handle the temper tantrums. Bob just can't handle it. When John has those temper tantrums, if Bob's around, he just leaves."

She also feels the need to protect the children through intervening when he is disciplining. "I'm constantly having to be their protector when he gets impatient and unreasonable which is quite often." She said that Bob told her recently,

> One of the biggest problems he [her husband] thought our marriage had is that (and he had a valid point) I intervened too much when he tried to discipline the kids . . . Part of the reason I do that is it is really hard for me to stand back because I disagree on how he does it. I feel like the consequences of what he is doing, is to me going to be down the line so much worse that I can't sit by and say go ahead and do it.

One of the other ways that Kelly protects the children is through setting up an environment where things will run as smoothly as possible, when she leaves the children with Bob. For example, when she took her oldest daughter to the ball game she made sure that John and Tanya had their teeth brushed, pajamas on, and were ready for bed. "They could stay up and play in their rooms until they were tired so he should not have any problems." However, she pointed out that this "reinforces the fact that he thinks he's doing everything right and they always behave for him. He doesn't

understand that I've already taken care of the things that could cause problems like refusing to brush our teeth or whatever."

One of the other difficulties Kelly described was that she views Bob as a "workaholic". When he does come home, she says that she often resents his intrusions.

> He is never home and probably the biggest disadvantage to him not being home with John is that when he does come home he doesn't know how to handle John. So then it does create problems. I think that he gets frustrated. Maybe part of the reason he doesn't want to be home is that he knows that when he comes home he's going to have to deal with John's problems.
>
> I resent it because I have worked so hard to create a positive environment for them [the children] which I've not always done successfully or perfectly. That's probably one of the reasons that I interfere more than I should when he's disciplining. It's because I resent him walking in off the street and thinking he knows everything about how to take care of these kids. He's never around.
>
> Maybe I've had to be in control so it's hard to let go. That is hard. We've done it all and so consequently I resent it. I deal with all the problems, I do all the mundane things, haul them to the swimming pool, haul them to Brownies, haul them to church school, take them here and there. Do their baths, brush their teeth, get their hair cut. I do everything. I take care of discipline. I feed them.

Kelly mentioned that she had thought of calling a counselor, but due to attending school and taking care of the children "did not have the time or energy" to deal with it right now.

Coping

Kelly described a variety of ways she copes throughout the course of the interviews. These included:

Changing Attitudes. She said she had to learn "not to expect too much, if you expect too much, you're going to set yourself up to fail." Kelly also described how she has changed the expectations she has for herself. For example, she said "I'm getting better because I've just decided the house is always going to be messy and it's not going to change." She also described how she had to learn to deal with conflicting priorities.

> People need to remember that when they [ADHD children] are out of control, you have to say, "So what if the dinner isn't done, so what if I have to be here, there, or the other place. Those things will have to wait."

Parenting Techniques. One of the techniques that Kelly emphasized several times was preventing problems by planning ahead. She described bringing books and paper and markers to church, planning special activities after shopping, and planning for special excursions.

> The biggest thing (I know I've mentioned it before) is to really think before [you go somewhere]. If I'm going to go someplace for instance I think ahead of what problems could arise and be prepared as to how I should deal with them. If we are going out to a restaurant, for instance, I will take great care in thinking about what he would enjoy doing at the table that will be quiet and that he will enjoy for maybe 45 minutes to an hour if our food is delayed, things like that.

She also mentioned that she might stay home rather than go to social events because of John's behavior. If she does go and sees his behavior deteriorating she leaves.

> I would see that he was starting to get wound up and if I was at a picnic with family or friends or whatever, I would take that time to say, "Ok, it's time to go

> home." That was my way and that wasn't a bad way because generally it stopped the behavior. We went home and everything might go fine - It might not but at least it wasn't in public.

However, she says that now she is learning ways of redirecting his behavior so she may not always have to leave.

> Now I can watch and deal with it without leaving maybe. I might be able to see him get wound up. Like the other day when we had company coming over. I let him know ahead of time that we were going to have company and he needed to be very careful that he didn't get too wound up, because it would be hard with all the people in the house. When I saw him getting wound up, I suggested he go outside. He was very happy to go outside. He got on his snow pants, the whole nine yards. Out he went and when he came in for dinner there were no problems.

She has learned to use a variety of redirection activities.

> As we are around these kids we do become very good at predicting. I can try to head off what I see coming by changing his activity . . . When he starts racing in the house if I can't send him outside then a lot of times I'll suggest a bath. He loves the bath, loves to play in the tub. Sometimes I'll say, "I'm cooking dinner would you like to help me." He loves to help. So I'm getting better at trying to do things other than just get rid of him or go home.

Kelly also emphasized the need to give John positive feedback.

> I do try to catch him being good. Because I want him to know that I'm not just going to be there telling him everything he's done wrong, which is really hard not to do, with any child.

<u>Techniques to Manage Her Own Emotions.</u> Kelly described on several occasions the need to be patient. "I make sure that my patience stays within reason, I know if I lose my patience and become a raving lunatic or whatever, . . . you

know - you just come unglued and you just can't deal with it any more and you lose control." She has trained herself to be very calm in highly stressful parenting situations.

> I remain extremely calm. It's almost like I'm not really there, I'm watching the situation and reacting how I think I should. It's almost like when he is really out of control that is when I'm at my best because I have to be. It takes a tremendous amount of patience and energy. But, it is a calming thing. I find myself very calm. Sometimes when you're trying to be patient with a child, inside you are very impatient. I don't feel that when I'm dealing with his screaming temper tantrums or if he's being really awful (which he can be at times). Maybe, it's a little like how people talk about the afterlife, when they are on the table and they come back and they leave their body and they are watching down. It's somewhat like that, I just find that there is this person that I can be. That this is the one I reserve and I keep it on hold. I can't use this person all the time. I become extremely calm. It's something that I had to learn because that was the only way I could be patient. Because I get very, very angry at this child, extremely angry. And yes, I would love to just wring his neck at times. But, in lieu of that I become very calm and very patient.

Stress Reducers. Kelly also discussed the different ways she uses to rejuvenate herself.

> When I just can't cope with things, there's a couple of things I will do. I will have a quiet time. I'll get the kids to bed early and I will read or maybe I'll watch a movie or just put on some music and kind of catch up on whatever I need to do. I also will visit with a friend. I have a couple of friends I can call on the phone and ventilate all I want to and they can return the favor.
>
> I will read, I love to read, I get very little time during the school year. But, every night I read even if it's only a couple of pages.

She stated that her greatest stress reducer was going back to college. She had planned to wait until her children were

older but made the decision to return earlier because she "needed to get out and get away from everything and do something for me." She said "that it seemed a little bit of heaven to go and do something for me." School gave her a break from her children and boosted her self esteem because it was an area where she could be successful. It also gave her an opportunity to have friends.

> It has completely changed me. My self-esteem is better overall. Not perfect, I still beat myself up a lot. But, my sanity has come back--most of the time. I know overall I just feel more positive and I feel happier, much, much happier than I was back then. I didn't even know how unhappy I was until I got a chance to get out with my peers. The only person I saw was my husband or if I saw someone at the grocery store or my parents or whatever. I never got the interaction as an adult with friends. So it has been a wonderful experience, a good, good decision.
>
> I had been so far down emotionally and so depressed. I don't mean depressed in that I was lying around on the couch depressed, I just mean I didn't have good self esteem. Here is something finally I can do. I can succeed at this. I have control over this.

Support From Others. Kelly talked about her doctor sending her a lifeline. She said,

> I think the biggest change came when I went to see my pediatrician and he came up to me and said, "Don't blame yourself, this is not your fault. You're a good mother. You're doing everything right. This is what's wrong." And it gave me back a little self confidence because I'd been beat down so long thinking I was a terrible person that couldn't raise this child.

The doctor also gave her permission to think of her own needs.

> He said do something for you. I was glad he told me that because we tend to get as parents or mothers (generally I think we get this more than men) the

> martyr syndrome. Where I have to be everything and do everything and have everything done and if I don't do these things, then I'm a failure.

Kelly's extended family has also been very supportive in providing both physical support and emotional support. Her mother watches her older daughter after school until Kelly gets home. She was also the only one that Kelly felt she could safely leave John with. Kelly said she often compared her sister's children to her own and wondered what her sister must think about Kelly's parenting. But Kelly said, "When all this transpired [the diagnosis of ADHD] my sister said, `You have more patience than I would ever have with that child.' So that was good. My family has been a godsend to me."

Kelly also saw a counselor. Although she only went four times, she said the counselor helped her learn to "pick her battles". She also has some supportive friends. She states, "I'm fortunate that most of the friends that I choose now are wonderful."

Kelly copes with having a child with ADHD in a variety of ways including; reflecting upon her parenting skills, developing techniques, employing stress reducers, and developing a support system. She is also beginning to choose activities, such as returning to school that will boost her own self esteem. But in spite of all this she says, "It's a daily thing . . . it's tough. You deal with it a day at a time. You can't say, `Ok this week will be

perfect' because you're setting yourself up for failure. You just deal with it." She also says, "that there is life after ADHD if we can find it . . . I have such hopes for the future and I feel fortunate that is wasn't something that we couldn't cope with." Kelly also emphasizes that being a mother of a child with ADHD has made her a better person. "I am a stronger, more patient person and probably a better mother overall. Because I have to be. I don't have a choice. No one is going to do it for me."

Sue's Case Study

Sue is a 42-year-old educator who is currently pursuing a doctorate degree. She lives in a small town near one of Montana's major population centers. She and her husband, Jerry have three children. Elaine, their 18-year-old daughter is in the Army. Josh, who is 20, is married and works as a clerk. Chris, their 12-year-old son is the only child who still lives at home. He was diagnosed as having attention deficit hyperactivity disorder (ADHD) five years ago. Following Chris's diagnosis, Sue read several articles and began to wonder if she had Attention Deficit Disorder (ADD). She was evaluated and diagnosed with ADD three years ago and is currently taking medication to alleviate the symptoms. Elaine was also diagnosed as having ADD.

In describing Chris Sue stated, "He is very creative, very bright, and very personable." "He likes to make

structures, to draw, and he comes up with unique ideas and solutions to problems." For example, he took his Connex (a plastic snap together building system) and added a motor from another item to make a moving structure. She stated that while he has trouble getting along with children his own age, he gets along well with adults and younger children. Chris also likes using the computer and his Game Boy (a hand held computer). In fact Sue stated that he takes the Game Boy everywhere.

According to Sue, his intelligence isn't always recognized by others because "people look at his behavior and make assumptions." She described some of Chris's difficulties as including "lack of organization, impulsivity, and when he is not on his medication sometimes his behavior is rather aggressive." If he has to sit for long he will get fidgety.

Chris was also very demanding during his younger years. One area that Sue described as difficult was getting him to sleep. She recalled when he was two and it would be 10:00 at night and he would be "ready and rearing to go." He also didn't take naps. This was difficult for Sue because she was pursuing her bachelor's degree at the time and needed to do her homework.

Chris also required close supervision. One reason for this was that he played with matches. Sue said that he would hide in his bedroom or outdoors and then light them.

Sue reported, "it was a lot of stress and struggle just to try to get him to behave." She felt that he did not willingly disobey. But instead it was due to his impulsiveness and high activity level. She stated, "The problem was his inner inability to perform." For example when they were in public, Sue described spending a lot of energy trying to get Chris to conform, "Chris stop, don't run, use an indoor voice." If they went to eat, he was very active, had trouble staying seated, and would make loud comments.

According to Sue neither positive nor negative discipline worked, "because young children are impulsive anyway and being hyperactive he was just unable to control his impulses." She stated,

> When he was younger, I spent all my time trying to stop him. I did a lot of time outs. Until he was on medication that was not effective. Spanking is not effective with ADHD even if you're consistent. If they're not medicated other than physically restraining them when they're really feeling hyper there's not a lot you can do. Time out is not very effective if they're feeling hyper because they are not going to stand in one place. They're not going to sit in one place. He'd get angry and kick the wall, kick the door. Actually nothing seemed to work until he was medicated.

When Chris started kindergarten "he had trouble sitting, he would call out the answers before waiting to be called." The teacher recommended retaining him in kindergarten due to his immaturity and Jerry and Sue agreed. But after the second year of kindergarten his behavior had not changed. Sue reported that the teacher told her, "We

did not give him enough attention and affection at home." When Sue requested an evaluation, the teacher refused.

Between kindergarten and first grade Chris played Little League. Sue said this is when "it really hit home to her" that his behavior was different from the other children his age.

> All the other little boys were sitting nicely and neatly on the bench and Chris was climbing the back stop and playing with the bats and helmets. I'd say "Chris sit down." He'd go and sit down maybe for a minute. Then he was playing with the back stop, playing with the bats, playing with the helmets. All the other little boys just sat the way they were supposed to. He was assigned to the outfield, a logical choice for a child who has trouble paying attention to the game. He would watch ants and watch the clouds and the jets pass by overhead. He would do anything but pay attention to the game. I don't think he even knew when the inning finished.

When Chris started first grade Sue discussed her concern about Chris's behavior with his teacher. After observing Chris for the first two weeks of school, the teacher called Sue and agreed that they should refer him for an evaluation.

Diagnosis and Treatment

Sue had Chris evaluated by a psychologist who specialized in ADD and ADHD. After Chris was diagnosed as having ADHD, he was placed on Ritalin. Sue stated,

> With the medication there was such an improvement in behavior that I did not dread taking him out into public, just to go to a restaurant and have him sit there and behave and not have people looking at me like why don't you control that bratty little kid.

She reported that the teacher also told her that she noticed an immediate change and that it "was like having a different child in class."

Not only was the change in behavior a relief to Sue but it was also a relief to know the cause of the behavior. When Sue described her reaction to the diagnosis, she said,

> It was a relief. A vindication that it was not my lack of parenting skills that was causing his behavior. I had been spending so much time trying to manage his behavior especially in public if there were other people around . . . I had spent so much energy just trying to manage his behavior that I was exhausted . . . It was a relief and I've heard a lot of people that are in denial. They don't want to admit that there is something wrong with their child. It was nice to know that it wasn't something wrong with me.

Chris also feels positively about the diagnosis and taking the medication.

> He knows what it is. He knows what's wrong. He knows why he takes medication. A couple of times he said, "I wish I didn't have to take pills all the time." But, he realizes that he feels better when he takes the medication. He feels more relaxed. People are more accepting of his behavior. His life is easier because he takes medication and he realizes that.

However, Sue stated as time went on the medication was not as effective.

> My son has a very fast metabolism and the Ritalin went through him in an hour and a half. That was the maximum dosage the doctor would allow. He had a very bad rebound effect. He was a little terror. He was absolutely filled with rage when it would wear off. He was in the second or third grade, we had a wooden bench outside and he literally broke the bench, that's how angry he was. He was doing karate type kicks to it even though he had never taken karate. He was kicking it and kicking it and kicking it. We decided at that point that something else needed to be done, that this was not working.

Sue then took Chris out of town to a psychiatrist specializing in ADHD. He switched Chris to a different stimulant medication, Dexedrine. Sue said, "It made a real difference. It was a gradual uptake and gradual wearing off. . . When it wore off it wasn't as dramatic." Recently Chris has had more difficulties and they are again adjusting his medication. At the time I was interviewing Sue, they were trying a new medication, Tenex, which was being used in conjunction with the Dexedrine. Tenex is an anti-hypertensive medication. Sue said,

> Chris is not hypertensive. But, somehow it works on other parts of the brain to help relax him. Since we have started that not only is Chris calmer and getting along a little better with the other students, he's also getting his homework completed.

Another benefit of this medication is that Chris can get to sleep more easily.

In addition to finding the right medication and dosage it is difficult for Sue to get the prescriptions filled.

> There are laws that say you can only get so much at a time and the company that fills our prescriptions will only allow us to get so much at a time. Which means that every time I get a prescription I have to go to see the doctor. So the insurance company is not only paying for medication, they are paying for a doctor's visit every time.

She reported that it is also difficult to find a general practitioner who is willing to prescribe the medication, so that you don't have to see a psychiatrist. For several years they have commuted 300 miles to see the psychiatrist. But, now a specialist has moved into the area and they are

able to see him. Sue said that not only does this process cost money but the visits to the doctor and pharmacy are time consuming. Since the medication is not handled by her local pharmacy, Sue has to obtain the prescription in a nearby town.

Also, although with medication Chris's behavior has improved there are still areas of difficulty. While Chris does not throw things, hit, or kick, he does still have tantrums. He will "pout, stomp his feet, slam the doors." While he used to yell according to Sue this is diminishing. When he does yell, he yells "in a very loud voice" things like "you're not being fair, I never get what I want." "Any changes in routine can trigger behavioral differences like difficulty getting to sleep at night or attention getting behaviors . . . such as interrupting, making smart remarks, trying to take over conversations."

But, Sue emphasized that one of the most difficult things to handle is the risk taking.

> I could handle the hyperactivity. I could handle a lot of the impetuous behavior. But, I could not handle the risk taking. He's had stitches in his head five times, he's had a broken arm, he just recently broke a knuckle. Every time there was an accident it was when he was not on medication.

Chris still has difficulty making and keeping friends. When he was younger Sue said he was very loud and still is if he is off medication. He also has difficulty "reading cues, the social cues from other children his age. Even at a young age he was viewed as being different by the other

children." Sue stated that he sometimes still has trouble at the bus stop with arguments. "The other kids have identified him as different and give him a hard time." Periodically, he also gets in physical fights at school.

Chris also occasionally has trouble dealing with some adults. He recently got kicked off the bus when "he got off the bus and said, `I am out of your jurisdiction now' and swore at her [the bus driver]." Sue described the bus driver as being "very, very strict. You have to sit with your feet forward. You cannot talk to your neighbor." She said Chris did this during a period of time when his stimulant medication was being counteracted by some other pain medication he was taking for a broken knuckle.

Impact on Sibling Relationships

Sue portrayed Elaine and Chris's relationship as being like "oil and water, they just did not get along because each was trying to manage the other's behavior." She emphasized, "If they were in the same room together they were generally arguing." "She tries to boss him around, tell him what to do. She tries to micro manage his behavior. He's not going to put up with it. He won't." Although Sue said that she and her husband have explained repeatedly to Elaine that they are the parents and that she is not in charge of Chris, she would still nag him about the way he sat, the way he held his pencil, the way he interrupted. In addition, Sue stated that Chris, "knew

every one of her [Elaine's] buttons and just started up at the top and worked his way down." According to Sue, it is much calmer and more peaceful at home now that Elaine has moved out of the house. She stated, "It's a terrible thing to say but, I am glad she's out of the house." Chris's oldest brother is also gone from home but Sue reported he and Chris got along ok.

Impact on Sue's Marriage

Sue stated her husband has had a hard time accepting the ADHD and "that our son's behaviors are due to the ADHD." She said he thinks, "my child can't possibly be damaged goods." She also stated that sometimes she feels he blames her. "I think sometimes he looks at it as my fault because well it's a genetic thing, so it's my fault."

Sue said, "I have tried very hard to educate my husband about this. But, he has been reluctant to learn about it. He said he gets tired of hearing me say, `Well this is typical behavior for an ADHD child.'" Sue declared, "it makes it difficult if you have one parent who doesn't want to take the time to look into it." "I think that if Jerry would come to terms and really look into it that he would be more understanding." In addition, since she is the household "expert" on ADHD she is expected to "deal with the school and with taking him [Chris] to the psychiatrist." Sue stated that this is frustrating for her and "causes stress in the marriage."

Sue said her husband gets irritated with the behaviors that Chris exhibits, "when he forgets, when he acts impulsively, or when he doesn't do things that my husband thinks are common sense." He also gets frustrated when Chris doesn't pick up his room. She emphasized that Chris "is definitely not organized" while her husband is "super militarily neat." She further stated, "He thinks that our kids are disorganized and sloppy because I set a bad example." Jerry and Sue also disagree about whether the behaviors' Chris exhibits are related to the ADHD. Sue stated,

> Jerry thinks I am using them as excuses and I am saying, "No, they are not an excuse. They're an explanation." I am not saying, "He should get off scott free if he misbehaves, I am saying this is why he misbehaves and so in terms of consequences we need to look at that."

Sue will say, "Why did he do it? Did he do it on purpose? No. Why should he be punished if he didn't do it on purpose? Why do you talk to him as if he had done it on purpose?" She stated that she finds herself in the role of "mediator" and "defense attorney." "That causes frustration on my part, I don't want to have to be a mediary."

The accommodations that are made at school are another area of disagreement for Sue and Jerry. Chris qualifies for a Section 504 plan which lists modifications that Chris needs to be successful in school. But, Jerry worries that if accommodations are made now that Chris may never learn to be successful in the "real" world.

> My husband's afraid that when he goes out and works and gets into the job market that he won't be able to cope. He says, "Well, when he gets a job they're not going to make adjustments for him, so he should learn how to go through school without any adjustments."

Sue stated,

> I guess he does not understand that 504 does include jobs. I don't ever see him getting a job as an air traffic controller. I can see there are many things that he would be able to do. I guess this has created a lot of tensions between Jerry and me.

In addition to the disagreements due to the differences in the perception about the ADHD and the way in which it should be handled, Sue said that after Chris was born they did less as a couple.

> Jerry and I stay home a lot because of it [ADHD]. Not so much now as we did. But, we hardly ever have anybody over. I do think a lot of it has to do with the ADHD. We haven't formed many close friendships with other couples.

Jerry and Sue do try to get away together one weekend a year and Sue said that she wishes they could do this more frequently. However, it is difficult to find child care. Sue said it is "almost like having an invalid. You feel like you can't go anyplace because nobody wants to watch them for you."

Impact on Other Family Relations

Sue said that her mother-in-law has told her, "I am a bad parent" and "I just use that [ADHD] as an excuse to let him [Chris] run wild." According to Sue, her mother-in-law "is not a very accepting person. Her idea of discipline is beating a kid. If you beat them enough you'll get them to

behave." In addition, her husband's family has different expectations for children than she does. "In my husband's family they expect the kids to just sit there and shut up and not participate in the conversation." Sue described a time when her mother-in-law came to visit.

> She wanted to go here and there and I had to drive every place and she insisted on sitting in a certain place and I knew that this was not the best seating for my children. It ended up that she hit my son on top of the head and I told her, "Don't you ever ever hit my children again."

Sue reported that her mother-in-law was so indignant that she left immediately, cutting her visit short. When I asked Sue if she felt that her mother-in-law was more disapproving of her as a parent with Chris than she had been with the other two children, she stated, "Absolutely, yes."

Sue described her parents as more understanding and as sharing her views about discipline. However, they have also stated that she has "poor parenting skills because of his [Chris's] behavior." She also said,

> A psychologist told me it was my good parenting skills that helped him to be so well adjusted and well behaved in the first place so he didn't really need a lot of counseling. He just needed help with some of his impulsivity and stuff. I passed this onto my mother and she said, "Oh, well he wasn't that well behaved in the first place."

Dealing With Schools

Sue discussed the schools several times during the interviews. She stated that Chris's first, second, and

fifth grade teachers were supportive. In describing his fifth grade teacher she said,

> Last year my son had a teacher who understood. She had been to workshops. She made the adjustments that he needed. Instead of doing a hundred math problems, she looked at them and said, "Well, do this many in this section and this many in this section and he did a satisfactory job."

But, this school year has been different. This year Chris has two teachers. Before school began this fall, Sue went in and had a conference regarding Chris's special needs. She told the teachers,

> These are the problems, these are areas where he has difficulty, these are things you can do to help. If you have a month long project, break it down and say at the end of the week I expect you to do this and this. I was told, "We can't do that." Which is self defeating not only for the child but it doesn't help the teacher any.

When Sue's suggestions were not followed, she asked for a Section 504 plan. Although Sue described one of the teachers as agreeable, she said the other "just sat in closed behavior, arms crossed, legs crossed, away from us." The teacher said, "Chris has to be responsible." Sue thought that the teacher who had appeared agreeable, understood her concerns. However, then the teacher called her one day and said, "Chris is choosing not to pay attention." Sue replied, "Sometimes with ADHD, it's not a choice." The teacher also sent home a test on which was written, "I am disappointed because apparently you weren't paying attention in class." Sue said these comments make her angry and made her feel like saying,

> "Well if you were a better teacher," which isn't fair either because she's doing the best she knows how to. Then the finger pointing goes on. Being a teacher, being in education I know that I cannot be looking at another teacher and say, "Well you know if you were a better teacher." That's as bad as looking at me as a parent saying, "Well, if you'd just spank your kid he'd behave."

Sue also said that she felt frustrated because even with the Section 504 plan, modifications were not made. At one point Chris brought home 107 language arts problems, where he had to underline the verb once and the helping verb twice, etc. Sue told Chris to do four in each section and sent a note to the teacher explaining that she had made the modifications as noted in the 504 plan. The teacher sent a note back saying, "I am glad to see that you're following through." Sue emphasized, "I don't think I should be the only one following through. I think the teachers should also follow through. The burden of my son's education should not be on me." Sue was also upset because the teachers were not following through with the information they had been given on how to reduce distractions for Chris. She said, "One of the teachers put him in a group with three other children with ADD so they were all sitting in the same place." When Sue found out, she complained to the principal. The teacher then made "Chris sit in the back of the room at a table, making an example of him. If you can't pay attention in the room, then you're going to sit back here." Sue said she was really irritated and again talked to the principal. She declared, "This past year I have had to be a very strong

advocate for him [Chris] because although the teachers claim to have information about it, having information and understanding it are two different things, it's just worlds apart."

In addition to being an advocate, Sue described tutoring Chris through 5 or 6 hours of homework a night. "I was having to sit there with him to help him through with it, to make sure he was on task." When I asked Sue what she did when she helped him with homework, she replied,

> I help him to stay on task. I read for him, he does not have difficulty reading, his reading comprehension is excellent but just the physical task of doing it takes time. It's just faster if I help by reading to him. Reading him the questions, making sure he understands the questions and the answers, helping him with study skills, like where are we going to find that answer and things like that.

Part of Sue's time is also spent in keeping Chris motivated.

> I let him take breaks because just sustaining focus that long is hard for anyone. I might let him watch television for a half an hour or something so he can relax and get back to work. Maybe play a game with him or something. Or we'll discuss something that has nothing to do with homework and then he can get back to it.

Chris chose not to participate in sports this year so he could get his homework done. When I asked Sue how she felt about this she responded, "I thought it was a shame that a child should have to make that choice."

Impact of ADHD on Sue

Sue discussed several times how time consuming it was to raise an ADHD child. This included the time needed to

manage his behavior and also the time needed for increased visits to the doctor and the school. Sue's time is also greatly impacted by the need to help Chris with his homework. She described her frustrations in assisting with homework 5 or 6 hours a night, "I had my own work to do, my own home work, and I had comps [comprehensive exams] coming up. I was frustrated not having time to do my own work because he wasn't getting it done." Sue stated that spending this amount of time helping Chris with his homework, "saps my energy. There are a lot of things I don't do. Social functions, things like that, that I do not participate in because I don't have the time or energy." Sue said that after Chris switched to a new medication, he was able to stay more focused in school and the amount of homework that he brought home was reduced which gave her a little more time. "Sometimes I even have time enough to wind down at night to go to sleep."

Sue's time is also impacted because Chris requires more supervision than a non-ADHD child. She stated, "I don't even like going and leaving him by himself at this age and I think that's because of things he's done in the past, it just makes me a little leery."

During the period of time that I was interviewing Sue an incident occurred that impacted both Sue's time and her feeling of stress. Chris broke his knuckle. It was in the morning before he had taken his medication and "he was

slinging his hands around and hit a dresser." Sue said their regular doctor was out of town so his partner had to see Chris. But when they got to the office there was an emergency and they were sent home. When they did get to see the doctor, he had another call regarding the emergency. Due to this, Sue feels that he may not have looked carefully enough at Chris's chart. "It was right there in front of him and he didn't make a connection between what codeine would do and the drug interaction and so Chris was acting like he did when he was not on medication and because of that there were problems."

Sue said that "Chris got thrown off the bus because of inappropriate behavior [related to taking codeine] and so I had to take him to school and pick him up after school which just played havoc with my schedule." In addition Sue said that her stress level was increased because she was unaware that he had been thrown off the bus until the last minute. As she was ready to leave to go to work Chris said,

> "Oh I forgot to tell you I got kicked off the bus." They [the school] didn't notify me and we have an answering machine and they could have left a message . . . So I got pretty angry. I took him in. I went into the principal's office and launched a complaint. I was irate to say the least. Things like that do add to my stress level.

She also felt frustrated because there had apparently been continuing problems on the bus.

> If she [the bus driver] had notified me that he was having problems on the bus I could have done something about it. But, she didn't. She didn't call me when Chris was talking out of turn and she moved him to the

> front of the bus. She did not notify me when he was talking to a friend and she told him not to and he kept doing it anyway. If she had done those things I could have acted on it and reinforced it at home. But she didn't and maybe it never would have escalated to this point.

It was not just the events that were stressful but the timing of the events that increased the impact.

> I had a very stressful week until I figured out there was the stress of breaking his hand, there was the stress of when the medication was not working well and then the additional stress of having him thrown off the bus and having to go back and forth and at the same time studying for my orals. I was the one who had to figure out why he was behaving that way, that it was the medication he was taking for that and so yes, that added a lot of stress I didn't need, at a time when it was not good to have additional stress.

Sue described her reaction to stress,

> I guess I become very restless. I have a hard time sitting still, I get angry, I can tell when my stress level is going up because my tolerance goes down and I get angry more and sometimes I feel sick to my stomach.

Sue also described feeling a sense of fear. "I guess occasionally a sense of hopelessness and fear. Will my son be able to make it in the world? I know I have, but." However, she also feels frustrated when her husband expresses these same emotions. "I guess I am also frustrated with my husband because he's afraid my son won't be able to make it." "It's as if the concern comes from a different place." When I asked her about the hopelessness, she discussed her frustration at always having to advocate to get her son's needs met.

> Hopelessness in that I get tired of having to go to the school all the time and discuss this and have to remind the teachers about it and remind the principal and the

> bus driver. I get tired of having to say, "You are forgetting, you are not following the 504 plan." I get tired of being the only one who's following it.

Sue also mentioned more than once that she feels lonely. At one point in discussing this she began to cry.

> There are lots of times when I would like to do a lot of the things I see other people do. Have friends over, play a game of cards, whatever and it gets lonely. It's not anger at him. It's just a feeling of loneliness. A feeling that, hey, it would be nice to have people over to entertain more.

But, she stated when friends do come over "it's frustrating and tiring trying to control his behavior." "His interruptions, trying to get in on the conversation and trying to hold a conversation with the constant interruptions make it difficult. So it's easier not to have people over."

Sue also said that her self esteem had been impacted by other's reactions regarding the ADHD.

> I didn't have a very good self concept to start with because of the ADD and having people tell me you'd be a better parent if you handled your son better, my husband not accepting it or not wanting to learn about it, that has had an impact. I guess if everybody tells you how bad you are you begin to believe them.

Coping

One of the ways that Sue copes is by dealing with her own ADD. She was diagnosed three years ago and is currently taking medication. She says, "When I take Dexedrine I feel normal, able to listen when my professors are talking about things that normally would trigger mind trips." The medication also "allows me to relax enough to sleep."

Stress Reducers. Sue also utilizes many stress reducers. For example Sue reads a lot. She states, "I guess that's an escape mechanism so when I feel stressed out I like to read and very often I go back to old books that I've read before that I have found satisfying and reread those." She also likes to take a "good hot bath" and plans a time for this in her schedule. "Every Sunday right after the Sunday morning news show, I go in and take about a one hour hot bath." She also regularly engages in storytelling at the schools, she declared that it is good for the students but also for her, "I guess it's one of the things I perceive myself as doing well."

When she is feeling considerable stress she said that, "I feel the need to have something to distract me, something pretty mindless, playing Game Boy or computer games can be pretty mindless."

Parenting Techniques. Sue has developed techniques to prevent behaviors from escalating. One is to let Chris know that his behavior is inappropriate by using the sign for "no" in sign language. Another is to have Chris go to his room when his behavior deteriorates. In addition, she tries to prevent problems by planning ahead so that Chris doesn't get bored.

> We take Game Boy everyplace, absolutely every place and books for him to read if he wants to read his book or Boy's Life or something like that. Something else to keep his mind busy.

According to Sue, some of Chris's past teachers have also been supportive. "They were willing to look at what the problem was rather than blaming."

Sue has also participated in counseling. However, she said that she did not find it very helpful because the counselors did not understand ADHD.

Summary

Sue uses medication, parenting techniques, stress reducers and seeks support from others as a way of coping with ADHD, however dealing with the impact of ADHD is still difficult for her as evidenced by the many times that she had tears in her eyes during the interviews. While handling Chris's behavior is hard for Sue, it appeared to be even more difficult for her to deal with others' reactions to Chris and their lack of understanding. This included dealing with her husband, her relatives, Chris's teachers, and people in public. Sue mentioned several times she wished people understood.

> People understand if you have a child who has an obvious problem, if you have a child who is blind or a child who is deaf or a child with cancer or something like that. They understand but, if it's something like this it's not visible. People just do not understand and since they don't understand they have to find a place to put the blame and usually it's on the parents.

She also stated,

> As much as I want to, I can't control somebody else's behavior. I cannot be responsible for what somebody else decides to do. I have shared with Chris my beliefs, my values. If he misbehaves, I let him know

risk taker. "He's like a crazy person, talk about risk taking you can really see that with him when he's on the ski slope. It's like straight down the hill and let's take this jump and let's see how high in the air we can go." Jim has also recently begun to wrestle which Sabrina describes as very valuable. "In wrestling they get him down on the mat. That's exactly what he needs is to do some of the physical stuff with adult males." Jim also loves to be outdoors "in mud, snow, rain, sleet, he's out at the creek fishing."

Sabrina also described Jim as very social although not always appropriate. For example, he likes to talk a lot to her and to everyone else. She said,

> He will go up and talk to anybody. One day this drunk had his arms all over my son and was giving him money for the machine and Jim didn't worry about it, he didn't even process that this man reeked of alcohol.

Jim is fascinated with knives. "When he was little, I'd go to the store or something and my dad would be watching him. I'd come home and I'd make sure he was tucked in and he'd have the butcher knives in his bed." Fire is also a fascination.

> He burned his grandfather's bed. He got under the bed with a lighter and it got up into the box spring and smoldered and smoldered and I kept smelling the burning. I could see the smoke but I couldn't see where it was until all of a sudden it started up the wall.

He still exhibits this type of impulsive behavior. Last summer he went to the school to close the windows and while

doesn't and I don't. We haven't had that kind of thing . happen in three years, so he's comes a long way."

Sabrina stated that the school community has also grown: She described the changes in two board members. Last year two board members had "locked me in the office and told me to my face" that "they didn't want to hear about special needs again, they were sick and tired of special needs, they had no place in this community and they wanted it out."' She responded, "Number one,, special needs are here. Number two, they will be addressed because that's our job. Number three, it's the law."

This year she said these board members are addressing special needs within their own families.. Some of the board members attended the workshop on ADHD and even stayed after the workshop asking questions. ?

She feels that she has been a change agent in the school.

> I would love to say, "I told you so." I would love to say, "It's all my doing.". I know it is. I don't need to say that to anybody. Whether,they know it or not doesn't matter at this point because the kids are getting more of what they need and I am leaving.

Impact of Parenting an ADHD Child on Sabrina

When Sabrina talked about how having a child with ADHD had impacted her she said,

> ADHD tends to rule the life, my life, the life in the household, the way things are done. I don't socialize as much, I don't have parties, I don't have people

anymore because he'll get so angry he'll be throwing Super Nintendo pieces all over the place." She explained that these outbursts may be precipitated by frustrations such as getting a low grade on a test. When he is out of control, he will at times act violently toward Sabrina.

> He likes to get real physical with me. That has really calmed down this year. Three years ago he would just beat on me and beat on me. Last year it was a little bit of that but not so much.

Sabrina said that now they both have learned the signs that this might occur and are learning to take steps to prevent the violence.

Sabrina said that Jim will sometimes leave situations and hide as another way of coping with his frustrations.

> We'll be at the community building and all of a sudden he'll be gone. Something would have happened. Somebody looked at him or said something. I'll find him underneath the wood pile or in the cement loader or somewhere in town. He'll just have gone and hidden. Now he pretty much just comes home, that's because he's getting more mature.

Although Sabrina described Jim's violent behavior as improving as he gets older, she also said that in some ways it is becoming more difficult to discipline him.

> I could physically remove him [when he was younger]. I could get on a one to one level where he would stop. Now he will just continue on. When I reach up to take his arm, if he doesn't want it, he doesn't want it. He pushes it more now than he used to. I don't like it. I am embarrassed because he does it in front of people. I would love to be a hitting mother. But, I don't go around hitting. I would just like to take him home, I want to take him out of it because I just don't want to have to deal with it.

pediatrician. Jim currently takes medication twice a day with an occasional third dose. If Jim is participating in a structured activity such as wrestling Sabrina will also give him medication on the weekends. However, if they are home she tries to avoid it.

> If we're at home and things aren't too crazy I will let him go without [medication]. Like if we have to work out in the yard or stacking wood or something like that and he starts getting an attitude and won't stop I usually have to redirect him and settle him down. Just sometimes, for my peace of mind, I'll give it to him just because I don't want to have to deal with his behavior all weekend.

It was also difficult getting the insurance to pay for the medication. Sabrina said it took a year and a half. However, the medication helps. Sabrina stated she can tell the difference when he doesn't have medication in him system. "He's more smart mouthed, more in my face." He also makes larger messes and will not pick up.

But Jim is resistant to taking the medication. Sabrina declared,

> He will play games, try to keep his mouth shut. He even went through a phase at the beginning of the school year where he took some of my meds and combined them with his. He put his in mine and mine is his and I noticed the difference when I took mine out because his pill is smaller than mine.

Sabrina said, "Jim doesn't want to be that special kid that everybody knows is on meds." He will ask her to just give him half a pill not understanding that the amount of medication is based on weight. She declared,

> He doesn't talk about ADHD a lot. Last summer he wanted to use it as the excuse for doing what he did.

> and very inappropriate. They basically thought that he was spoiled rotten and I hadn't done something right. Then last year they basically thought he was spoiled and needed a tougher hand. Then they began seeing that he couldn't control a lot of things and he was trying. Then they began seeing the changes. He matured a little bit and more and more of the support he was getting kicked in. This year I've seen board members and adults go to ADHD workshops and parenting classes and ask questions so that they could coach better.

This winter several of those involved with Jim participated in an ADHD workshop. Included were his coaches, teacher aids, and the woman who owns the restaurant he sometimes works in. While the workshop was scheduled for one and one half hours, the twelve people who were there stayed an additional hour and one half, asking questions.

Sabrina said the people who interact with Jim now handle him more appropriately.

> They see the change in Jim and they think that he is just marvelous. They see the inappropriateness now and instead of getting mad and angry and threatening, they give him some space. They don't verbally get into him now. They back off and tell him to take a break for five minutes. Not that, "You blew it, you're bad, go away for a while." It's "Let's take a five minute break."

She feels that this has impacted not only Jim but also other children in the community. "They've got some others [ADHD children] that they'll do the very same thing with. They're finding that it really works positively and the calmer they can be and the more they listen then the faster the kids come back."

Sabrina said Jim also has a very supportive tutor. Although the tutor is paid by MRM, Sabrina stated she would

upsetting to her. In relation to some remarks made at the ADHD workshop she stated, "There were a couple of comments about Jim that really upset me. They were both from the same person even though she tries her very best to support me." She also emphasized, "You know I have the support but I don't have the friends. I've got acquaintances and working relationships but there's not the friendship here." Jim also has few friends in their town. Sabrina said this is partially due to the small number of children living in town. But it is also because peers reject him due to his behavior. "His peer interaction tends to be very reactive and they don't like it. He's gotten so much better but it's still not acceptable with the standards that they have for buds so to speak." She said, "the kids don't understand a lot. They really want to but they'll make bad and nasty comments and then Jim will lose it."

Reactions From Sabrina's Family

Sabrina's mother died around the time that Jim was born. Her father later moved and now lives in the same small town as Sabrina. Her brother works on a ship and stays with Sabrina when he is on leave. Sabrina describes her family as "dysfunctional." She said they have "trouble with boundaries" and the females in the family have been very "co-dependent." She stated when her brother stays with her he has a difficult time dealing with Jim.

She is also concerned about next year and has worked to get a specific IEP hoping that will make the transition to a new school smoother.

> Jim's IEP is exactly what he needs. This is exactly what can be provided and what I expect. As a parent I won't sign anything else or sign a waiver to let the school get away without doing certain things. Moving the way we are I know exactly the type of things I want to key in on so that I don't lose him and that he can continue on.

But one of the most difficult challenges Sabrina described in relationship to school was trying to balance her role as mother and teacher. Jim often spent time in her classroom. In addition, as head teacher she was often called in to deal with discipline. "They pulled me out of the classroom the first couple years. The teacher did that whenever it got really bad because she couldn't handle it." Generally when this happened Sabrina said she would "put him in the office and just shut the door and five or ten minutes later he would calm down enough to go and wash his face." But one day she described how she "lost it."

> He just jumped in my face and was screaming and pushing at me and hitting me with his fists. I just picked him up took him in the Xerox room, shut the door and gave him one big mother whack. And I said, "Oh God, I am ruining my child." I walked out the door and shut it. I was standing outside the door and shaking like a leaf. An art teacher was there and she just put her arms around me and said, "It's ok, it's ok." I said, "I can't believe I just did that. I try so hard to separate school from mother."

But Sabrina said that Jim has grown in this area. "When we first moved here Jim needed me 24 hours a day and now he

> over. It causes fighting to keep the house clean. I choose what is important and I am real limited on it.
>
> I don't go shopping, out to eat, or to parties and that. Number one, I feel guilty leaving him at home, it's hard to get a baby sitter or if I take him then he might lose it or he gets out of control and then I have to get angry and deal with it. I just would rather not have the chaos and the upheaval so I just don't go.

She also stated that sometimes she is not invited to events. "They tell me I am not invited because they just can't handle Jim. Their kids don't want to handle Jim and they are sorry." "It hurts." But not going out also can become a cyclical difficulty.

> I don't go out and do a lot of the socializing because of the ADHD and being embarrassed and not wanting the hassle. It makes it more awkward when you do want to sit and just shoot the breeze because I am so used to being on purpose and so focused. Because I don't let myself go out a lot and just socialize I tend to stay home even more because I'll have to think of something just to talk about that may not be school related. I don't want to work that hard, I don't want to bother.

While not going out or having others over does limit some problems and the feeling of embarrassment, it also causes feelings of loneliness and isolation.

> It's very suffocating, the worry, because then you don't act, you stay home more because you don't want to go out and worry about what's going to happen. You don't have people over to your house because you're concerned about what will happen and how they will perceive it and that's very suffocating. It's like living in a prison at times. I don't go to all the parties. You know going away parties or birthday parties because ADHD kids do not handle chaos, a lot of people and that kind of stuff. It's very difficult for them.

Several times Sabrina discussed the energy and time involved in raising a child with ADHD and the impact this

This then leads to a feeling of depression. "I am not clinically depressed. I go in and out of it. I get help from the doctor. I am on Prozak right now myself so that just keeps me constant."

Sabrina stated that sometimes she breaks down and cries. However, then Jim reacts to her tears.

> Jim just ends up being hysterical because he knows that I am crying because of something that he's done. He sees himself as being really bad and wrong. You know, I am not saying, "You're bad or wrong, I love you. Sometimes I don't like the things you do." Sometimes I don't like him when he does it. But, I always love him and he knows that.

She declared that Jim's hysterical reaction makes her feel guilty and to not as freely express her emotions in other situations. This has been an area she has been working on with her counselor.

In addition to her reactions over Jim's behavior she also said that she reacts to others' opinions regarding how she should parent Jim.

> I get really angry. I would love to know how to do things differently, to make it different. Then I get very defensive. After a while I know what I am doing is what needs to be done. Sometimes I need help seeing that.

Sabrina further stated, "As a parent of an ADHD child you can't please anybody." She also wishes that others understood how hard she tries to be a good parent.

> I don't think anyone could agonize more than I do to try to do the right thing, to raise him where he can make the choices that will be best for him. It's not always easy and happy. I'd like to stick my head in the sand sometimes. I haven't been able to a lot. I think you can more with normal kids and you can't with

the emotional feeling of panic about my house being clean because I just can't fight it any more." "I've had to compromise in certain ways. I didn't recognize it as compromising for quality of life at first. I just don't have the fight anymore. It was like pick your battle."

She stated that she feels that her experiences as a parent of an ADHD child have also helped her to progress personally. In discussing an upcoming move she said,

> You know being a parent of an ADHD child has helped me be a risk taker . . . I know I can make it work, I can run a school and teach a classroom and be a single parent and raise an ADHD child. I can go down to New Mexico and find something to help me pay for the bills so I can go to school, I know I can do that.

She also said that her personal experience with ADHD has helped her grow professionally. "I have such an understanding down to my very gut feeling about special needs . . . I really, really relate to kids very well and I teach at a level that reaches children."

The Decision to Move

During the weeks that I was interviewing Sabrina, she made the decision to move to New Mexico to pursue a master's degree in special education. This decision was very difficult for her to make. One reason is that they will be leaving the security and the support of the small town where they have lived for the past three years. Now they are moving to a large community where Jim will need to learn about the dangers of scorpions and rattle snakes and gangs.

> What finally made me able to deal with this is that after all of this is done I will have more financial security to give him more that will make him happier, be it voice lessons, more activities, living in a town with more possibilities.

She said that the increased income will also help Jim with his future.

> He'll be college material or trade material and he's going to need more help emotionally and financially. If he wants to go somewhere where I can't go then that means I can pay someone to support him emotionally. I also need to have money to do that.

She feels that the decision to move has been more difficult because of Jim's ADHD.

> I think my going to grad school has been harder than it would be for some people because of the effect that it's going to have on Jim with his ADHD. It's much more dramatic than just going and doing it. It's been harder for me to do this than I think it would be for a normal person . . . It will be harder in some ways for him and then there will be more I'll have to deal with.

Coping

Parenting Techniques. One of the areas that Sabrina described several times was the need for clear boundaries and consequences. During the course of the interviews she gave several examples. When Jim replaced his medication for hers she told him "If I couldn't be safe in my own house, he would not be here." When he set off the fire extinguisher at the school, she called his therapist. "With his therapist I called 911, I put him on probation. I think it was harder on me than him. It really did wake him up. I brought in another agency, the juvenile probation agency."

has to study. Just bringing that into the home is so hard on us."

Sabrina also tries to provide legitimate outlets for Jim's behavior. For example, since he likes to start fires, Sabrina has him light the wood stove. Since he has so much energy Sabrina encourages him to direct that energy into sports and creative activities.

Sabrina also said that as Jim is getting older she is trying to be more honest with him about her feelings. "I am real up front with Jim you know I can't take any more right now. I need you to be quiet for a while." She has also developed a hand signal. "When I put my hand up that means stop, stop talking, stop doing whatever."

Stress Relievers. Sabrina utilizes a variety of stress relievers. She said she likes to take bubble baths. "I love bubble baths and my girlfriend sent me one of those pillows that you blow up and put in the bath." She also enjoys reading and stated that she has been doing more of that lately. She is also starting to use her bread maker again. "I am making bread and that feels good." When she feels too stressful, she engages in a physical activity. "I get very industrious and do dishes, do laundry or I'll get things done just because I need to expend some energy and I don't want to expend it on my son, angry type stuff or I'll leave." She mentioned that sometimes she will go down town and get a cup of coffee all by herself.

> I am deathly calm. I almost talk in slow motion. I keep everything on a level, very slowly and also just sit and listen. I can't hear anymore. I process it but I don't take it in. It's like, "Ok you're running at the mouth." I'm listening. I am hearing it. I see that he's off his rocker. I can't handle any more so I'll just let him spew whatever he needs to spew.

Another technique that Sabrina utilizes is focusing on what she is physically doing.

> When things are really stressful and it's getting to be too much what the counselor told me to do is say, "I am here, I am walking down the hall, I am here walking down the hall." Focus on the here and now. Literally put everything right there right now. Not trying to take any more in . . . My intention is to be focused right here, right now. I am not going to lose my cookies over so and so, getting all upset. I am handling things. I am here right now, focusing.

Summary

Sabrina uses a variety of methods to cope with having a child with ADHD. These include medication, therapy, changing expectations, utilizing a variety of parenting techniques, gaining support from others and using stress reducers. But in spite of all she stated, "Raising my child is the number one and most important thing. He just happens to be ADHD which means it takes more . . . It takes more energy, it takes more thought, it takes more patience. I mean you have to lighten up on everything."

Sabrina said in an ideal world she would have a larger house that had a Lego room and space where Jim could build and keep creations. There would be "male role models to go horseback riding, to shoot hoops, to do woodworking." In an ideal world, "I would hope that all ADHD kids would be able

Chris, is 12 and has ADHD. He is the youngest of three children and is the only child who still lives at home. Sue and Chris's older sister have been diagnosed as having Attention Deficit Disorder (ADD).

Kelly is also married. She, her husband, and three children live on a ranch. Kelly is a student who commutes two hours a day to attend college. John, her son, is six. He has ADHD and is the middle child. Kelly suspects that her husband also has ADHD although he has not been formally diagnosed.

One of the mothers was referred through a support group facilitator, another through a parenting class instructor and the third had heard that I was doing the research and volunteered. The participants were initially contacted by phone and I used a screener questionnaire to determine if they were eligible to participate (see Appendix B). Each mother qualified, consented to participate, and was eager to share their story. Due to this eagerness, initial phone conversations lasted 1 hour to 1 hour and 15 minutes even though I was able to explain the purpose of the study, the time commitment required, and to complete the screener questionnaire in approximately 15 minutes.

Interviews were conducted using a general interview guide approach which listed topics and issues. However, the sequence and wording of these were varied to allow the interviews to flow in a more conversational way. Many of

not surprising since Jim, Chris, and John all have ADHD which is characterized by an inability to sustain attention, impulsivity, distractibility, difficulty concentrating and poor monitoring skills. ADHD is also often associated with extreme temperamental characteristics such as negative mood, short persistence, low frustration tolerance, excitability, and a quick temper (Linden, Zalenski, and Newman, 1989). The common behaviors that the mothers described in relationship to their children included, the child engaging in risk taking behaviors and having accidents, experiencing difficulty making friends, demanding attention, setting fires, having tantrums, experiencing trouble with sleep, having a high activity level and being creative.

Risk Taking and Accidents. All three mothers described their children as risk takers. For example, Sabrina said that when Jim goes down hill skiing, "he's like a crazy person, talk about risk taking you can really see that with him when he's on the ski slope. It's like straight down the hill and let's take this jump and let's see how high in the air we can go." In describing John, Kelly said, "He would climb trees as a very small child not even out of diapers." "He would jump from tables to couches that were five and six feet apart." Sue stated that Chris has had numerous accidents and that these usually have occurred when he was not on medication for his ADHD. "Chris has had stitches in

with the constant interruptions make it difficult. So it's easier not to have people over."

Kelly discussed having less time for her other children because John demands so much attention.

Sleep Problems. Kelly and Sue both described their children as difficult to get to sleep. Sue said that as a young child, Chris would be "ready and rearing to go" at 10:00 at night. In describing John, Kelly said, "He couldn't settle down. We had a lot of throwing the toys at walls and such. Every night and every nap time was very difficult." Both Sue and Kelly said that when their children were toddlers they did not take naps and didn't go to sleep until nine or ten o'clock at night.

Sabrina said that Jim does not have too much trouble sleeping but that he likes to go to sleep to music and would like to play it all night long. She stated that Jim "needs the noise."

Tantrums. Each of the mothers also reported that their children had tantrums and that these tantrums were often precipitated by minor events. Sabrina said Jim would "scream and yell and holler and cry and throw things and hit himself and anybody else he could lay into." This included hitting his mother. "Three years ago he would just beat on me and beat on me." Although this behavior is less frequent than in the past, Jim will still throw his Nintendo and has

with arguments and occasional physical fights with his peers. Sabrina stated that Jim also has difficulties with peers. She said,

> He does not have a lot of control compared to other kids. His peer interaction tends to be very reactive and they don't like it. He's gotten so much better but it's still not acceptable with the standards that they have for buds so to speak.

She reported that the other children "don't understand a lot. They really want to, but they'll make bad and nasty comments and then Jim will lose it."

John is only 6. Since he lives on a ranch, he does not generally have friends over. However, Kelly described John as having difficulty with his siblings and also with other children at Sunday school. She said that he hits and throws things at his sister. She also reported, "The church school teacher told me that he was being mean and he had kicked such and so for whatever reason and wouldn't mind worth a hoot."

Fire setting. All of the mothers described their children as having a fascination with fire. Sue said that when Chris was younger he needed constant supervision because he would hide and light matches. Jim also liked to play with fire. Sabrina reported that he had once burned his grandfathers bed when playing with a lighter. Kelly in discussing playing with matches said, "Joel is fascinated with anything dangerous. But, I try to eliminate all those things from his life."

> At first I absolutely could not accept it. Then it was "What did I do wrong?" Then it was, "It was his father." Then it was, "What did I have to do?" And then, "I can't do it all by myself." Then it was, "Do it." It's not my fault.

Medication for the Treatment of ADHD

The participants stated that each of their ADHD children was placed on medication as a way of alleviating the ADHD symptoms. Each of the mothers described this as very helpful. Kelly said,

> It was a drastic change, in two weeks he was diaper free. His speech all of a sudden started coming very quickly and things were just instantaneous as far as behavior changes. They weren't perfect because he was doing all these things for so long. But they were so much better.

Sue said that both she and Chris's teacher noticed a drastic change in behavior. She also declared,

> With the medication there was such an improvement in behavior that I did not dread taking him out into public, just to go to a restaurant and have him sit there and behave and not have people looking at me like why don't you control that bratty kid.

Sabrina stated that she can still tell the difference when Jim does not have the medication in his system. "He's more smart mouthed, more in my face. He cannot pick up, cannot keep his stuff in his space."

However, the mothers also stated that medication was not a miracle cure. Kelly expressed this sentiment when she said, "Medication did not solve the problem completely. You need behavior management." Even with the medication each of the mothers said that behavior problems still occur.

it has to do with the ADHD." She also stated that when they do have friends over, "It's frustrating and tiring trying to control his behavior." Kelly said that she had similar experiences,

> I hesitate to have them [people] over if I think it might be a problem. I don't need criticism. I have had friends that I know disapprove. They don't really say anything but you kind of get the gist that they don't think your method of discipline may be appropriate and so consequently you don't tend to invite them over much, because you know you're going to have to do something while they are there. That's just standard procedure. So it [ADHD] does affect friendships.

It also impacted her ability to go places because it was embarrassing to take him but also difficult to leave him with a sitter.

> I got so that I just didn't want to go a lot of places because it was too difficult. It was embarrassing to go and have to constantly deal with this child . . . I didn't feel comfortable leaving him with anyone but my parents. They were the only ones I felt knew him well enough and knew how to handle him and knew how closely they needed to watch him.

Sabrina also stated that she stays home more and has visitors in less often. In addition, she said that she is excluded because of her son's behavior. "They tell me I am not invited because they just can't handle Jim. Their kids don't want to handle Jim and they are sorry . . . . It hurts."

Marriage. Sue and Kelly shared many similar concerns regarding the impact of ADHD on their marriage. They both indicated that their husbands did not understand the ADHD.

didn't do it on purpose? Why do you talk to him as if he had done it on purpose?"

Sue and Kelly both handle their disagreements with their spouses over discipline by coming to the child's defense. Kelly stated that she is John's "protector." Sue described herself as "mediator and defense attorney." But, this role also causes problems. Kelly described this.

> One of the biggest problems he [her husband] thought our marriage had is that (and he had a valid point) I intervened too much when he tried to discipline the kids . . . Part of the reason I do that is it is really hard for me to stand back because I disagree on how he does it. I feel like the consequences of what he is doing, is to me going to be down the line so much worse that I can't sit by and say go ahead and do it.

Sue also discussed the lack of time that she and her husband have together. She said that they stay home more, have fewer people over, and due to the difficulty in getting someone to care for Chris they get away together less often.

Sabrina is not married. However she reported that she does not know how she would have the time or energy for a relationship. She stated, "I don't want to get in a relationship that's going to expend energy that I do not have because I am doing the very best I can to handle everything else I have to handle and I don't have the energy. I don't have enough anymore as I see it."

These same sentiments were also expressed by Kelly. She stated that she felt that she and her husband should probably go to counseling. But, she said that she "did not have the time or energy" to deal with it right now.

> People need to learn that when they [the ADHD'child] are out of control, you hav.e to say, "So what if the dinner isn't done, so what if I have to be here, there, or the other place." Those things will have to wait.

Because of the .impulsive, risk taking behavior the mothers also said that their children needed more supervision than most children. In describing this Kelly stated, "You just have to program yourself to be on a constant vigil, to watch what's going on." In addition, since their ADHD children didn't sleep as much as other children, they needed supervision for more hours. Both Sue and Kelly described this as especially difficult. When Chris was two Sue said she was a student. It would be 10:00 and she would want, to do her homework and Chris would still be "ready and rearing to go." Kelly reported how important "adult time" was to her and how she missed having time for herself in the evening.

When their ADHD children reach school age, the parents must also deal with homework. Sabrina has a tutor who works with her son Jim. But-, Sue described spending 5 or 6 hours an evening helping her son with his homework. Because he is so distractable they can only work for a short time and then will take a break.

In addition to homework, visits with schools, counselors, and doctors were also described as time consuming. Sabrina traveled 120 miles a week to take .Jim to the counselor. Sue discussed having monthly visits to the doctor and needing to go to a pharmacy in another town to

behavior. Both Sue and Kelly stated that their in-laws have unrealistic expectations for children, especially ADHD children. This included the expectation that children should sit quietly. They also both stressed that their husband's families believed in using "corporal punishment" to make children behave and that they did not. Kelly said, "I would have trouble with this [corporal punishment] for any child, but especially with John."

All three mothers also felt like their relatives disapproved of them as parents. Sue stated that her mother-in-law told her, "I am a bad parent" and "I just use that [ADHD] as an excuse to let him [Chris] run wild." Kelly talked about how her in-laws lack of acceptance affects her parenting.

> Where they are so critical of how I deal with my kids it does make it very hard. I do cope differently and I get much more frustrated than I normally would. Because if they are around, it's almost like I feel like I'm being tested to see if my kids are going to behave.

Although John was diagnosed with ADHD several years ago, Kelly and her husband have not told her in-laws about the diagnosis or that John is on medication. She feels that they would not approve.

Sabrina's brother works on a ship and stays with her when he is on leave. She said that her brother doesn't understand Jim. "When Jim messes up the computer and it takes me four and a half hours to reboot the whole thing, my brother would just kill him." Sabrina stated, "When he

Sabrina and Sue also described some teachers as being supportive. The teachers that were viewed as helpful did not provide information about ADHD or parental support. But, they helped through making classroom modifications and thus not making life more difficult.

John has not yet started school. However, Kelly discussed her fear of him beginning school. Kelly placed her oldest daughter in the closest school. But with John, Kelly is investigating several options. She would like a situation where the teacher has experience working with ADHD children, has a small class size, and who will "handle him in a positive way."

Dealing With Their Own Emotions

The mothers involved in the study also expressed having frequent, intense emotions in relationship to dealing with the ADHD.

Isolation. All three mothers described the isolation they experienced as a result of having a child with ADHD. Both Sabrina and Kelly used similar terms "like being in a prison" (Sabrina) "I felt a little bit like a prisoner at times" (Kelly) to describe their feelings in relationship to not being able to have friends over or to take their child out in public.

Sue said that this reduced time with others made her feel lonely. At one point in discussing this she began to cry. She stated,

Damage to Self-esteem. Both Kelly and Sue discussed how their self-esteem was impacted by parenting a child with ADHD. Sue said,

> I didn't have a very good self concept to start with because of the ADD and having people tell me you'd be a better parent if you handled your son better, my husband not accepting it or not wanting to learn about it, that has had an impact. I guess if everybody tells you how bad you are you begin to believe them.

Kelly conveyed that she was also impacted by others' opinions about her parenting. In addition, she stated that her inability to control her son's behavior impacted her self-esteem.

> I felt like a failure. It doesn't matter what you do this child misbehaves. It doesn't matter how patient you are, how loving you are. They do the same thing over and over again. Every time you're around other people they make it clear that they think you're not disciplining appropriately.

Kelly described going to the doctor that diagnosed John as having ADHD. He told her, "Don't blame yourself, this is not your fault. You're a good mother." She said that was the beginning of feeling better about herself. "It gave me back a little self confidence because I'd been beat down so long thinking I was a terrible person that couldn't raise this child."

Frustration With the Behavior. Both Kelly and Sabrina discussed how frustrating it was to deal with their children's behavior. Kelly said,

> It can be too demanding. This is a terrible thing to say but I finally understood how some people actually hit their children in anger, because it is extremely

each day with the children rather than having them cared for in the town near the ranch, is so that John could be in a child care "that knew about his problem." She stated, "I worry about him being criticized and knocked down, because he is not easy."

Hopelessness. During the interviews the mothers in the study used the terms helpless, hopeless, depressed, and discouraged many times to express their feelings. Sue said that she sometimes feels hopeless. When I asked her about this, she replied,

> I get tired of having to go to the school all the time and discuss this [the modifications for ADHD] and have to remind the teachers about it and remind the principal and the bus driver. I get tired of having to say, "You are forgetting, you are not following the 504 plan." I get tired of being the only one who's following it.

While Sue described this feeling in relation to dealing with others, Kelly said she sometimes feels discouraged and hopeless in regard to dealing with her son's behavior.

> When I try really hard to use time out or consequences and try to give choices and when none of those things work I feel so helpless. There are so many times that you feel helpless. You feel like you have no control, you're never going to have control again, nothing works. It's really difficult because there are so many things in your life that happen but you have a certain amount of control or you can fix them or you can deal with them and make them better. This you can't sometimes. It's not going to happen.

She stated, "There were lots and lots of times that I felt very, very stressed and depressed. Sitting down and having bouts of crying was not unusual."

Growth as a Result of Parenting an ADHD Child. The three participants all stated that having an ADHD child has helped them to grow. Kelly said, "I am a stronger, more patient person and probably a better mother overall because I have to be. I don't have a choice. No one is going to do it for me." Sabrina stated, "You know being a parent of an ADHD child has helped me be a risk taker . . . I know I can make it work, I can run a school and teach a classroom and be a single parent and raise an ADHD child." She also said that it has helped her grow professionally. "I have such an understanding down to my very gut feeling about special needs . . . I really, really relate to kids very well and I teach at a level that reaches children." Sue also asserts that she is a better teacher and advocate for special need's students because of parenting an ADHD child.

Pervasiveness of ADHD in the Lives of the Mothers

Time and Energy Demanded. All three mothers described raising their ADHD child as extremely time consuming and demanding. First, the mother must deal with the child's behavior, including temper tantrums which occur at unpredictable times. Kelly described how everything else in her life was put on hold so she could deal with John's tantrums, which might last for 45 minutes to an hour. She said,

get Chris's medication. Both Sue and Sabrina also reported needing to be advocates for their children. Sue said that she had many meetings with the teachers and principal this year.

The mothers all also said that they had difficulty finding child care so that they could escape the pressure. Sue stated, "It is almost like having an invalid, you feel like you can't go anyplace because nobody wants to watch them for you." In addition to the difficulty in finding child care, Kelly reported her fear in leaving John.

> I couldn't leave him with a sitter, I worried. I worried about the sitter hurting him in frustration. Not that I ever had sitters that I worried would do that. But, this is not a normal thing. You don't know what a sitter would do. Or if they would watch him carefully enough.

Impact on Other Areas of the Mother's Lives. In each of the case studies the mothers depicted having a child with ADHD as impacting all areas of their lives. Kelly said, "My life has changed so dramatically, I don't know what it would be like [to not have an ADHD child]. So many things do center around making sure John doesn't have a problem." She further stated, "It makes a difference. Your whole life is rearranged for this child. It has a big impact on everything you do." Sabrina expresses similar sentiments,

> ADHD tends to rule the life, my life, the life in the household, the way things are done. I don't socialize as much, I don't have parties, I don't have people over . . . . I don't go shopping, out to eat, or to parties and that.

my son, angry type stuff." Sue said that she plays Game Boy (a hand held computer) or computer games to distract her from the stress. Kelly will try to arrange a quiet time for herself.

They also each reported that they have at least one good friend that they can call and talk to. They emphasized that the friend accepted them and would listen without judging. When I asked about these friends being phone friends instead of having friends in the same community Sabrina said that this kind of relationship worked best for her because it did not expend the time or energy that an on site friend would demand. She also said this friend had known her from childhood. Sue stated that her friend had known her "before she became a parent."

Both Kelly and Sabrina also discussed having received support from counselors. Sue said that she had also gone to counseling but found that it was not helpful because the counselor was not familiar with ADHD or ADD.

Sabrina described receiving support from MRM (Managing Resources of Montana). This includes financial support to hire a tutor. She reported how relieved she was when the MRM case manager told her, "You don't have to do this alone."

When the immediate stress is too extreme both Kelly and Sabrina utilize a technique which Sabrina refers to as "disassociation."

> One of the things that he did was that mom had got some red spray paint and he took it in the bedroom and sprayed my suitcase when it was open. He sprayed all my clothes and sprayed the bedspread. I just started . crying because I was so mad that he destroyed so many of my clothes and even though I couldn't **do** a whole lot about it, I was very upset with iti (Focus group two)

A father described his 6-year-old son's destructiveness. "I built a deck outside our house. I came home one day and he [his ADHD son] had taken nails and a two-pound sledge and pounded nails all over it" (Focus group one). "I have the' battery drill and I've come home and found all kinds of holes in the walls where he has done some drilling" (Focus group one). Another mother said, "Well he did put a little‘ hole in the door. He wanted to see through.the door I think" (Focus group one).

Insatiability.' Several parents also described their children as insatiable. One mother said,

> My dad took them miniature golfing and went to visit and went to the craft show and he figured that was enough. But, there was a lake close by and my son just had to go to the lake too. My father just saw it as ungrateful and that he wasn't satisfied. So I tried to explain that and get him a little more understanding. He's not ungrateful, it's just that he's insatiable.■ (Focus group two)

Another said.

> She always wants something more. Like you would just buy her something and then she'd say, "Well, can I have this?" We'd say, "You've got this other thing, aren't you enjoying that? Don't you appreciate that?" She would just want more and more and morei (Focus group three)

They also reported changing their routines. Sue said that they get up earlier "to get their brains in gear" and when they eat meals they read the paper or watch TV because visiting at those times of the day does not work for her family. Sabrina discussed feeding Jim when he was hungry regardless of the time of day.

The participants also employ many parenting techniques. Both Kelly and Sabrina discussed "picking your battles." All three mothers also described utilizing prevention techniques such as avoiding situations where the behavior is likely to occur and planning ahead. Kelly described this,

> The biggest thing (I know I've mentioned it before) is to really think before [you go somewhere]. If I'm going to go someplace for instance I think ahead of what problems could arise and be prepared as to how I should deal with them. If we are going out to a restaurant, for instance, I will take great care in thinking about what he would enjoy doing at the table that will be quiet and that he will enjoy for maybe 45 minutes to an hour if our food is delayed, things like that.

Both Kelly and Sabrina use the sign for `no' in sign language to let their children know that their behavior is unacceptable.

Sabrina has a tutor to work with Jim as a way of preventing problems. She said that if she is helping him with homework, "He comes home and will have screaming rages . . . He's mad at me because I am telling him he has to study. Just bringing that into the home is so hard on us." Sabrina stated that she has also been working on establishing clear boundaries and setting consequences.

activities that enhanced their self esteem. When the immediate situation was too stressful both Sabrina and Kelly engaged in what Sabrina described as "disassociation". But in spite of all this, the mothers still portrayed their families as being strongly impacted by the ADHD.

The participants were impacted not only because of the child's behavior but also because of others' reactions to the behavior and their emotional response to the behavior and others' reactions. For example, when going out in public they must not only deal with the behavior the child exhibits but also others' reactions to the behavior which then can cause the mothers to feel embarrassed and curtail the amount that they go out.

The three mothers' lives were altered by having a child with ADHD. They described their time and energy as being effected. They depicted nearly all significant relationships as being impacted including those with their spouse, friends, relatives, the ADHD child, and other children in the family. Since they stayed home more and had fewer people over their more casual relationships were also effected. Relationships with schools and teachers were also described as being more difficult because of the ADHD. Their emotions were also impacted. Kelly, Sue, and Sabrina described having intense, frequent feelings of isolation, guilt, frustration with the ADHD behavior, worry, hopelessness, and frustration and anger with others for not

confidentiality the focus groups were numbered rather than named. With participant permission, all meetings were audio taped and transcribed. Before the focus groups began the participants completed permission slips (see Appendix F) and questionnaires (Appendix G).

At the completion of each focus group, data was consolidated and categorized. Categories were developed which would account for a majority of information and which led to both "internal homogeneity" and "external heterogeneity". A summary of the focus groups was then written. Quotes were chosen that were representative of the group and that were most clearly articulated. However, since the two mothers who participated in both the individual interviews and focus groups revealed no new information in the focus groups and the information they had previously supplied had been included in the case studies, quotes from these mothers were not used in the focus group summary. If contradictory information was given, even by one person, this was noted in the summary. Since the goal of the focus groups was to gain new insights and also to use the focus groups as a means of triangulation by reducing the amount of researcher control, the interviews were conducted using a nondirective approach (Morgan, 1988). This approach led to more emphasis on the participants' points of views. One advantage of this approach to focus groups is that it allows the group interaction to dictate what topics are

probably would figure it out. `Well lets see, what did I do?' He would not have a clue" (Focus group two).

Several participants expressed concern that their children did not have friends. A mother of a 12-year-old daughter said that she feels that her child's behavior contributes to this.

> She is just now figuring out that she needs to act decently to other people to have them do that in return. She was diagnosed when she was six. So this has been six years of me and her dad telling her over and over and over, "Your friends don't like it when you do that." "If you're going to act like a baby no one is going to want to be around you." That's the hardest part for me. It's the social part. It's her not having friends. Friends don't call. (Focus group three)

Another mother described other children rejecting her daughter.

> This weekend we went to a soccer tournament and no other kids would even talk to Carol. They wouldn't talk to her at all. It was like she was an alien from outer space. This little girl who has ADHD refused to be around her. If Carol sat down the other little girl got up and moved. She said, "I don't want her eating with me." (Focus group three)

High Activity Level. High activity level was another behavior described. In describing her son before he began taking medication a mother said, "He had a lot of body movement, rocking back and forth or kicking or chewing an eraser off instantly or picking up something that is near him having to play with it" (Focus group one).

pencils, things like that, a stabbing type of motion" (Focus group two).

Participants also described how their ADHD children will get violent with them when they are out of control. "I have a lot of bruises. My son likes to hit, scratch, kick and bite" (Focus group three). Other parents stated that their children manifest their frustrations differently.

> His anger is manifested in a different sort of way. He sort of internalizes things. You can see it's a Vesuvius and then all of a sudden he's saying things like, "I don't like myself." "I don't know why I'm like this?" (Focus group three)

Another mother said,

> Nate starts to cry more when he gets frustrated. He gets uncontrollable and he feels so much and he can't come down. He will start to cry and goes into that kind of a mode as opposed to hitting or things like that. (Focus group two)

Destruction of Property. While destruction of walls, doors, and toys occurs through tantrums, it also occurs due to impulsive behavior. One mother said that she had left her 8-year-old son in the doctor's waiting room when she went in for an appointment.

> The nurse called me right afterwards and said, "I don't know how to tell you this. But, this does happen sometimes. It looks like someone has poked 42 holes in one of the leather cushions in the office and we're pretty sure it was Nate." (Focus group two)

One mother said that she normally keeps anything that the child may misuse out of his reach. But when they went to visit her mother the environment was not as controlled.

Fire Setting. Several parents mentioned their ADHD child's fascination with fire. One father in focus group one described how his 6-year-old child was referred for an evaluation after setting the neighbor's car on fire and then setting the hall of their apartment on fire the following day. Following these incidents he was evaluated as having ADHD. Another mother described how her son started a fire in their kitchen,

> He likes fire. He started a garbage bag in the kitchen on fire and he had a temperature of 102 that day and had not been off the couch. I was unpacking some stuff from my grandparents because my grandfather had died. So we'd been back to Maine and I had brought some boxes back. He had a temperature of 102 the day I had unpacked and I thought, "He's on the couch, it's a great time to do this." Of course it was packed in all kinds of newspaper in a plastic bag. One of the things I had brought back, I don't know how to describe it but you put the matches in there. I hadn't even thought about it when I packed it. I thought, "I shouldn't have brought the matches with me." But, I didn't think. So they were just sitting on the counter, the bags were there. For some reason I went into the other room for a moment and he got up during that moment, saw those matches, right into the paper. I was just really lucky to get the bag out of the house. (Focus group two)

Creativity. Several participants also stated that their children were creative. One mother said,

> The first grade teacher was the one that thought that Carol had it [ADD]. It was more or less her creative ideas. She would think really different, not normal. One of the things she [the teacher] asked was, "What lives in houses?" Well, Carol came up with time. "Time lives in a house." (Focus group three)

> Sometimes the second dose seems like it doesn't even work at all. There are times when we give it to him and it just is like it doesn't even work. Like last night, I gave him his medicine. I'm sure he took it. But, it's not working. It's just not working. The bad part of it when they do come off of it sometimes there is the depression that goes along with it. You get the feeling that here is something not quite right, not quite working in their system. (Focus group one)

Impact on Relationships

Marriage. Most of the participants that discussed marriage felt that their marriage had been impacted by having a child with ADHD. Participants stated that disagreement between the parents regarding discipline played a major role in this. One mother said,

> Ethan has definitely caused a lot (not blaming Ethan) but the issues of discipline have caused a lot of friction between my husband and I. Actually, the last year is probably the best we have gotten along and I feel a lot of it is just due to the fact that things have changed a lot for Ethan. So all the relationships have changed a lot. (Focus group two)

A father in focus group one who has ADHD himself discussed the differences in the way that he and his wife discipline. He said that his wife is the "protector of the children and the mediator. She is the one who is the referee in our house. She referees all the little mini wars that go on all the time plus trying to keep the house going." He said that they disagree on "almost everything" including discipline.

> We disagree on my actions. She thinks that you should approach it in a very calm and careful and quiet way and solve the problem. When one of them [ADHD child] is beating up on the other, it's like I see what is going on and I don't approach it in a calm, quiet way. I do it quick and get one off of the other one. I get

because if he goes he will be going to Washington. I won't be there and I am really afraid of that." She also said, "Part of me does think, `Oh, I could use a break.'" In discussing it further she stated, "If he would take him for a week in the summer it would be like heaven for me. But, then it's going to be like hell for Troy, I'm not willing to do that to him."

Another mother stated that she and her husband were going to be getting a divorce. She said that the time she spends with the ADHD child as well as her husband's inability to cope with the ADHD behaviors have contributed to this.

> My husband and I are going to be getting a divorce and one of the major reasons or one of the major factors is my son. John and I have been married for 30 years and we have had no children during that whole time period and then the last time I got pregnant we decided that I would try and see this through . . . He cannot put up with Nate . . . It's become very obvious that John can not handle Nate's outbursts. He has a hard time dealing with him on any kind of long term basis. By long term I mean over a whole section of the day, even. You know he just can't take all of his energy. You know it's not controlled. (Focus group two)

One single mother discussed how having an ADHD child not only affects marriages but any meaningful relationship.

> I'm single now and I really have these doubts about whether or not I'm going to ever find anybody. I'll say when someone asks me out and I start to get to know them, I'll say, "Well, there's something you need to know about my son." Then they meet him and they never call back. I can prepare them. I can say, "He's really active. He has ADD. He is going to want to wrestle with you." And they'll say, "Oh that's fine. I like kids." Then it's not fine obviously. It's so difficult just to think about this. You know I might have to be single. If I do find someone, I want that

> homework with Karl tonight. You need to do that." All of a sudden he's coming out of the room going, "How do you get him to learn this?" I mean that's just this year and he's getting it. I was managing him too, because I didn't want him to get upset. But the load got too big for me. (Focus group three)

Siblings. Several participants stated that the ADHD child was violent with siblings. One said, "You had to watch him a lot with his sister, because he would be vengeful and hurtful to her and basically was mean to her and didn't like her" (Focus group 2).

Another stated,

> He was really little when she was just born. It wasn't always a mean thing. Like he went to rock the cradle and it was real fast. He wanted to carry her around the neck and those kinds of things. So we had to put an alarm on her bedroom door, so if the door was opened while she was sleeping it would go off. It would wake her up but she would be safe. He does still do the hitting and kicking. I mean she may antagonize it. But, there's no stopping or thinking [on his part]. (Focus group two)

Many of the parents also said that the ADHD child did not respect the other sibling's space or belongings.

> He [the ADHD child] won't stay out of their space. He won't stay out of their rooms. He just finds something that interests him and he will play with it or he will take it out and just store it in his own little place so he can go back to it when he wants. (Focus group one)

One father stated that his solution to this problem was to put hooks on the sibling's doors so the ADHD child could not enter.

Other parents discussed how the ADHD child would embarrass their siblings.

One mother discussed how she and her husband's expectations are different for their ADHD child than their other children. She said that the other children have a difficult time understanding this. In discussing keeping their bedrooms clean she stated,

> I don't care if he [the ADHD child] gets it real clean. But with the girls I care. They see that difference. Because the kids are so extreme even the girls are very extreme. I just use that example. Because one loves sports and one of the girls loves music. Well they don't love each other's activities. So Jarod just loves different things and he is just different and we have to make some allowances for this difference. (Focus group one)

Other Relatives. There were few mentions of relatives in the focus groups. The discussion that did take place generally regarded the lack of understanding on the part of relatives. One mother of a 9-year-old ADHD boy said that her mother treats her child as a "half person" and that her attitude influences the rest of the extended family. She said,

> We do many things when she comes out. Our lives are very fast paced and Jarod is not in his routine life and they [ADHD children] love routines so he has more trouble with that. He'll misbehave . . . . I notice that she treats him very different and it's geez, it's almost like she thinks he has a disease of some kind . . . She treats him as less than a person. They don't even make eye contact. They don't talk to him, like they do the girls. (Focus group one)

Another mother stated that her mother did not like her son's behavior and this has affected the amount that they have visited.

> I'm in a foreign language class and I decided kind of on the spur of the moment on a Friday night to go to the pizza place with the foreign language club just so I could be with some other adults, knowing that my instructor and his wife have no children and don't really like children, except for their pets. This was before Troy was on Ritalin after school, so his medication was completely worn off. He has this difficulty. He wants male attention. There was an older man and his wife there who we never met before and this man started engaging Troy in play. For any other child this would be ok. Before I knew it Troy was hitting and kicking and wanting to wrestle and being loud. I warned this gentleman before hand, I told him to please not get him started because he won't stop once you get him started. He said, "Oh no. It's fine. It's ok." I could tell by the end of the night that this man was frustrated because Troy wouldn't stop. We finally just ended up leaving because it was just too much.

She also described having to leave one of her best friend's wedding reception.

> I was at one of my best friend's weddings and I was in the wedding party and afterwards at the reception I had to leave. I had to take Troy because there was no one to watch him. We had barely even started and I was in tears.

Interactions With Schools

When participants discussed schools, the teachers appeared to be the key as to whether parents viewed their child's year as successful or not. Parents described both teachers who were willing to accommodate their child and those that were not. In describing a teacher who was very helpful, a mother in focus group two said,

> I was really lucky. She [the teacher] was wonderful and if I'd had my way she would have moved right along with him [her ADHD child]. She was just a kind person. She didn't know a lot about it [ADHD]. But, she took the time to learn about it and she was willing to work with his activity issues and deal with it. We became

the IEP]. You can ask them, you can beg them and they won't. You can have all the IEP's you want and they are not going to comply with them" (Focus group three).

Medication was also an issue. One parent described a teacher who felt that medication should resolve all the problems.

> I have a teacher right now who prodded and prodded me and finally I went and had his dose [medication] increased because she said it wasn't doing what it was supposed to. After I had it increased, she called me and said she's not seeing the change. It finally hit me that she thinks that just because he is on medication that he is going to act like every normal kid in the classroom . . . It hit me that she thinks that because he is on medication he's going to be all better. (Focus group two)

Another parent described dealing with a teacher who did not believe children should be on medication.

> I took him to school and I forgot to give him [ADHD son] his medicine. When I went to school to pick him up at noon, the kindergarten teacher is waiting with him. Now George is normally a good student. She says, "Are you having trouble at home?" I said, "No more than every day, I have trouble at my house all the time. Oops, I forgot to give him his medicine." She is one who does not believe in the ADHD. She is a teacher who does not believe that the medicine should be there. But, I think it is a good reminder for her about once a month that I send him to school without the medicine. (Focus group one)

Parents also discussed homework with several describing homework as ruling their lives. One mother said, "It's like an hour a subject for homework and they bring home about five subjects" (Focus group two). Another mother said that homework was "the focus of her life" (Focus group two). She declared that the majority of the time that they do homework

> I tell her to do her homework and if she doesn't have it done she's the one that has to pay for it. She got a D in science because of that. She is a very intelligent little girl. But, she has to realize that if you don't do your homework you're going to get bad grades and I'm going to yell. The grades matter a lot to me. They always did. But I'm not going to take responsibility for the homework. I won't. I refuse. (Focus group three)

Several parents also mentioned that they wished they knew the purpose of the assignments.

> I get really upset when the teachers do not want to share their agenda with you. Because their agenda is generally very different from the agenda that is being presented to the kids. I mean I don't know why they are reading this little book or why they are doing those writing samplers. Maybe doing the writing samplers is just to make certain that the kids follow directions. (Focus group two)

Participants also stated that sometimes they felt that they were in adversarial roles with the schools. One mother said,

> You go visit with the teacher and say, "I know that it's difficult. I know that, too. I know what you are going through. I have to deal with him at home and I understand the frustration. But, if we can compensate in this way it will be easier for the both of you, I think." Sometimes I find a power struggle going on. I don't get that. We should both be working for the best interests of the child. We should be on the same side. (Focus group three)

One mother discussed taking parenting classes that the school had provided. She said that the classes were very helpful. They were also free and child care was provided.

Impact on Parental Emotions

The parents in the focus groups described several emotions that they experienced in dealing with the ADHD.

> One thing that happened last week was that I was picking him [ADHD child] up and there is always a battle between the front seat and the back seat. I thought we had come to an agreement on that. But, then his sister wanted to sit in the front so she being four was crying and having a little fit while he just got mad and started just screaming at the top of his lungs. We were parked in the parking lot at the school and parents and teachers were there and here is this blood curdling scream. So I am trying to calm her and shush him and the embarrassment of it and the frustration of things being so out of control. (Focus group two)

A father expressed similar feelings, "Of course you deal with embarrassment and public humiliation and so on and so forth. I'm kind of numb to that now" (Focus group one).

Frustration With the Behavior. When discussing the feelings generated by having a child with ADHD one mother said, "Frustration would be at the top of the list for me, when you have to repeat things over and over and over" (Focus group three). Another mother discusses her specific frustrations.

> My worst time is the morning with the constant, "Do you have your clothes on? Do you have your teeth brushed? Did you find your shoes?" She's always dissolved in tears. "I don't know where my jeans are?" "Did you look in the laundry room?" "No." "Did you look in the drawer?" It's really frustrating. Really. (Focus group three)

Another parent also shared his frustration with mornings.

> Oh yes, mornings are really fun. No medication, you know a person would have to get up at 5:00 A.M. to medicate him for the mornings to go smooth. He gets up and out of bed and terrorizes everyone. He wakes up everyone else. He is my little alarm clock and he just terrorizes. He goes through the rooms and just picks and teases. I have to get to him and sit down and explain to him. And then off he goes and does it again. But, I medicate him right away. (Focus group one)

Hopelessness. One father shared his feeling of hopelessness.

> I think in the past that I dealt with it [the ADHD] pretty well. But I think that is why I'm depressed now because everything finally caught up with me. Just the repeated stress over and over and over. Trying to deal with the situations at hand, being the leader of a single parent family, just everything. I used to be a real happy person, always smiling and really into school and all that kind of stuff. Like I said, finally now everything caught up with me and I can't do it anymore. (Focus group one)

Exhaustion. A feeling of exhaustion was also described by several parents. One mother said, "I could say that for the most part I have felt tired through a lot of this. That is probably the overall feeling that I get" (Focus group two). Another stated,

> I never have time to do anything because I'm always the mediator and the disciplinarian and everything all of the time. I just basically have to chase him around. You could have him go outside but that don't do him no good because he would just go outside and get into mischief outside. It's just a constant battle. (Focus group one)

Coping

Reducing Stress. The parents in the focus groups discussed a variety of ways that they cope. Several parents said that they make a conscious effort to do things that they enjoy and that reduces stress. The techniques mentioned most often were reading and exercising. One mother said that she folds laundry to reduce stress.

activity, and waking the child up early to give them medication and then letting them go back to sleep until the medication is working.

Parents also discussed making changes in the environment. This included putting hooks on the doors of siblings to prevent the ADHD child from entering, putting alarms on the door of infants' rooms to warn the parent if the ADHD child entered, and "child proofing the house". In describing the need to keep the ADHD child safe one mother said,

> Well as adults we have to intervene and if we're not going to take the proper steps to intervene then we can't just go back to the child and say, `Why did you play with those matches?' Hasn't he done it 300 times before? He's going to play with matches. I consider that a parent error or an adult error. We know what their limitations are. My role as a parent is to make that child's world safe whatever that child is. (Focus group one)

Other parents described how they prevent problems from escalating by removing themselves. For example, one mother who has an older son discussed leaving the situation when she cannot cope with the behavior. "At that very moment you know maybe I can't even think straight. He's hit a cord or something. So it helps me to get back on track. `I'm not discussing this now. I'm walking out on this one'" (Focus group three).

A few parents mentioned taking time out themselves. One mother said,

> I used to have to go down to the bedroom and say back off. If I used the word back off and do this with my

Support From Others. Several parents mentioned that CHADD, an organization for children and adults with attention deficit disorder, was helpful for them in coping with ADHD. One mother said, "I like to go to CHADD because that gets me out there with other adults and it helps me to hear other people going through the same things and their ideas and stuff" (Focus group two).

Another mother said while CHADD was helpful for her it was difficult for her to get together with the members outside of meetings.

> It's fun for me to get together with other ADHD parents and compare notes and solutions and coping things and anecdotes. But Nate doesn't do well getting together with other ADHD kids. They bug him. He's better with the average kid which surprises me. (Focus group two)

Parents also said they received information about ADHD through reading articles and books and researching ADHD on the computer. One mother in the initial phone conferences mentioned that she spent several hours a day on the computer researching ADHD.

A father described a comprehensive plan involving both himself and his child provided through Managed Resources of Montana (MRM).

> I sought professional help. I got hooked up with MRM. This has been a drastic turning point in my family. Just knowing that you have that is like a security blanket. We've even got a crisis intervention plan and she [the case manager] was involved in it. But it never has gone that far. (Focus group one)

He said that they have meetings every three months which include all those involved with the child and parent.

"We discuss what he is doing, what he used to be, how he is doing now and what we hope he will be doing later." He said that the plan includes relief time for himself, a tutor for his son, and activities to keep his son busy.

Summary

In the focus groups several areas were discussed by participants. The main categories emerging were the behavior of the ADHD child, the impact of parenting an ADHD child on marriages, the challenges for the siblings of an ADHD child, the lack of understanding on the part of other relatives regarding ADHD, the difficulty with schools, parental emotions, and coping strategies.

In discussing their ADHD children, the parents described several behaviors that the children exhibited including; difficulty making friends, high activity level, tantrums, destruction of property, insatiability, fire setting, and creativity.

Most of the parents who discussed their marriages described their child's ADHD as adversely affecting their relationship. Differences between parents regarding discipline were frequently mentioned as causing conflict. The spouse not being able to handle the behavior of the child was also referred to. The few mothers who did not feel their marriage was impacted discussed having similar beliefs about discipline and husbands who actively assisted in managing the child.

ADHD, embarrassment, frustration in regard to the child's behavior, worry, guilt, hopelessness, and exhaustion.

Parents described a multitude of ways of coping with the ADHD ranging from prevention of problems to engaging in stress reducers. The degree to which parents were coping with the stress ranged from a single mother who said,

> Just yesterday I was walking and I thought I should just keep walking. Then I thought I'd get tired. For me that's as simple as it is. I just thought I should just keep walking. No, I'd probably make it so far and then I'd get tired. It's like that sums up my life in a nutshell. He's my son. I can't leave him. I know I don't cope very well. Putting him to bed at 8:00 is probably the only thing that I do. (Focus group two)

To another mother who stated,

> I do a lot of things from tai-kwon-do to whatever. I read a lot. I'm busy doing a book. I go to the CHADD meetings when I can. I started taking Spanish. I don't feel that I'm not able to handle most of that stuff. I don't feel badly about that at all. I'm sorry that my husband can't handle it. (Focus group two)

But even this parent who used many ways to personally cope with ADHD stressed how having an ADHD child had drastically impacted her life. She stated that she and her husband were going to be getting a divorce and that one of the main reasons for this was because her husband was unable to cope with an ADHD child.

focus groups was written. Quotes were chosen that were representative of the group and that were clearly articulated. If contradictory information was given, even by one person, this was noted in the summary. The final step in data analysis was to examine the findings of the focus groups and the case studies for the emergence of patterns. Information was included which emerged consistently in both these settings. As the categories were reexamined this final time, overriding themes were identified. These final themes were: the ADHD child's erratic behavior, altered relationships, social isolation, difficulties with schools, emotional upheaval, medication quandary, and a coping repertoire. These then combine to create a megatheme "the unremitting struggle".

The ADHD Child's Erratic Behavior

In describing their ADHD children, parents described several behaviors including: lack of social skills and difficulty in making and keeping friends; unpredictable, violent tantrums; destruction of property both through tantrums and through impulsive behaviors; fire setting; high activity level; insatiability (neither attention nor possessions are enough); risk taking and being accident prone; sleep disturbances; and creativity.

Although we could predict many of these behaviors based upon the common diagnosis of ADHD, it is only by understanding these behaviors in the context of the family

disagreements regarding discipline, what methods to use and what the child should be disciplined for. Participants felt that their spouses did not understand ADHD, its ramifications, or impacts. Several of the mothers stated that they were often the child's defender or protectors, interceding on the child's behalf. Marriages were also impacted by the time and energy that parenting an ADHD child demanded with several mothers and one of the fathers stating that they shouldered a greater share of the burden than their spouse for raising the ADHD child.

Participants described their ADHD children as needing greater supervision at an older age than most children and as having fewer friends. This combined with the difficulty in finding child care caused couples to have less time alone.

However, there were a few mothers in the focus groups who said that their marriages were not impacted. In each case the mothers also stated that they and their spouse agreed regarding discipline and that their husbands were active participants in parenting their child.

There has been little previous research regarding the impact of ADHD upon marriages. However, previous studies have described a higher separation and divorce rate among ADHD families (Barkley, Fisher, Edelbrock & Smallish, 1990; Brown & Pacini, 1989).

participating in the individual interviews stated that they had relatives who disapproved of their parenting, especially in regard to discipline. Although there was less discussion about relatives in the focus groups the same concerns emerged. Parents described feeling that both they and their ADHD children were unacceptable to their relatives.

Three parents described having some relatives who were supportive. These relatives provided assistance in two ways; they provided moral support and acceptance of the parent, and/or they provided child care giving parents some relief from their responsibilities.

Social Isolation

Consistent with a study by Weiss (1990) parents described becoming socially isolated as a result of parenting an ADHD child. This occurred for several reasons. They had less time and energy to devote to friendships due to the demands of parenting an ADHD child. Previous friends sometimes displayed disapproval of the child's behavior and the parent's method of disciplining resulting in the parents having less interaction with these people. They also had fewer visitors to their homes because the child's behavior embarrassed them. One mother stated that her child's behavior caused her to be excluded from parties and events.

In addition, they described having fewer casual encounters with others. They confronted difficulties with their children's behavior and disapproval of themselves and

their children in most social settings including parties, church, stores, and restaurants. Participants also had difficulty finding child care. This caused them to go out in public less often.

The social isolation and resulting loneliness were primarily described in the individual interviews. Although no conflicting data emerged in the focus groups, this was not an area that they heavily discussed.

The Difficulty With Schools

Schools posed special problems for ADHD parents. Unlike other social situations, attendance at school is mandatory. In addition, the number of hours and days devoted to schooling cause it to be of great significance in both the parent's and child's life.

When participants described schools, it generally was in relationship to specific teachers. Those teachers whom they described as helpful, made modifications without being asked. They also described teachers as helpful when they kept parents informed about projects, homework, and assignment due dates.

However, most discussion in relationship to schools revolved around the dissatisfaction that parents experienced. They discussed two primary areas, the teacher not following IEP's or Section 504 plans and the time and involved energy in supervising homework.

emotions were expressed but due to the lack of time for any individual participant there may not have been an opportunity to share all of the emotions experienced by each participant. The most common emotion shared in the focus groups was frustration that others often did not understand ADHD, instead blaming the child and parent. However, the parents also described the growth that they had experienced due to these difficulties.

These findings are consistent with what Weiss described as the "struggle" and parents feelings regarding it. The parents in her study used words like angry, exasperating, cheated, horrible, fearful, upset, furious, and guilty to describe their feelings (Weiss, 1990).

Coping Repertoire

Similar to what was described in a previous study (Naseff, 1989), all the participants (except for one mother) described using a variety of coping techniques. Included were both problem-focused coping that attempts to change the stress producing situation and emotion-focused coping that attempts to deal with the emotions caused by the stress (Folkman & Lazarus, 1980).

As a way of altering the stress producing situation parents described many techniques including giving their children stimulant medication, limiting the battles through changing their expectations, thinking ahead of what difficulties might arise and planning for them, modifying

work on coping with parenting a disabled child- (Frey, Greenberg, & ,Fewell, 1989; Rousey, Best, & Blacher, 1992). But, the majority of children in these studies have had Down Syndrome or developmental delays. Previous research pointed out that families with children who have Down Syndrome experience less stress than parents whose children have autism or conduct disorder (Noh, Dumas, Wolf, & Fishman, 1989). Conduct disorder is often a comorbid condition with ADHD. Therefore conducting research on coping which is specific to the ADHD population may be necessary.

.It would be useful to continue to examine variables that may contribute to the stress and coping that ADHD parents experience. For eg. the age of diagnosis, different combinations of treatments, and different educational settings.

Many studies'(Barkley, 1988, 1989; Barkley, Karlsson, Pollard, & Murphey, 1985; Barkley, Karlsson, Stelecki, & Murphey, 1984) have examined the impact of stimulant medication for ADHD upon family relationships. However,. researchers have conducted these studies in lab settings. It is important to continue to explore the impact of therapeutic levels of medication on parent-child interactions in a naturalistic setting.

Identifying and examining the characteristics of schools that have been successful with ADHD children and families is another area that researchers need to examine.

duration (Lazarus & Folkman, 1984). Event uncertainty refers to the predictability of the event occurring with unpredictable events considered to be more stressful. Temporal uncertainty refers to when the event is going to happen. Again, not knowing when an event will occur causes more stress. Several ADHD families discussed the unpredictable nature of their child's behavior. Kelly, a mother participating in the individual interviews, stated that the only thing that is predictable is that you know something bad is going to happen, you just don't know when. Families also referred to the need to be constantly vigilant not knowing when this extra vigilance will be needed.

Duration refers to the length of time that the stress continues. ADHD is a chronic situation with new demands for adaptation as the child's behaviors change and new outside forces are encountered such as new teachers and neighbors. Families also must continually deal with new crises related to the ADHD. For example, Barkley, Fischer, Edelbrock & Smallish (1989) found in a longitudinal study which followed 123 ADHD children that the children with ADHD were three times more likely to have failed a grade in school or to have been suspended. They were eight times more likely to have dropped out of school or to have been expelled. Most likely, this would be only one of the struggles impacting these families.

As the child matures the family may also need to adapt to additional diagnosis. Barkley, et al. found that 60% of the 123 ADHD children in their sample qualified for a diagnosis of conduct disorder or oppositional defiant disorder in adolescence. Lazarus and Folkman (1984) also state that the feeling of control a person has over events influences their ability to cope. Situational control appraisal "refers to the extent that a person believes that he can shape or influence a particularly stressful person-environment relationship" (Lazarus & Folkman, 1984, p. 69). The belief that one has little situational control negatively influences both the person's emotions and their ability to cope. Participants in my study discussed the lack of control they felt over their child's behavior as well as the lack of control over others' reaction to the behavior. Many parents expressed the feeling that they did not feel competent in parenting their ADHD child. While they had these feelings internally, they also reported how this was continually verified through their interactions with others. This was also found in a previous study by Sobol, et al. (1989), who found that ADHD parents described the cause of their children's behavior to be more unstable than the control group. The ADHD parents also indicated they had lower expectations for achieving future compliance from their ADHD children.

share difficult thoughts and experiences. The focus groups provided additional breadth through involving more participants. In addition, where the individual interviews involved a dialogue between one other person and myself, the focus groups produced data with little input from me. However, the categories that emerged were similar in both the individual interviews and the focus groups.

I invited those who were involved in the individual interviews to also participate in the focus groups. I had anticipated that new information would surface from the exposure to others' thoughts and feelings. However, this was not the case for the two participants who attended the focus groups at the completion of their individual interviews. I had followed Lincoln and Guba's (1985) recommendation and continued to conduct individual interviews until the material being shared became redundant. The fact that the two mothers shared no new information during the focus group meetings is likely a further verification that the data had been exhausted.

Critical case sampling was used to select participants. In critical case sampling it is presumed that if these experiences are true for this particular group one would expect it to be true in other cases as well (Patton, 1990). However, due to the small numbers of participants and the lack of a random sample the results are not necessarily generalizable.

Recommendations

Professionals

Parents repeatedly described the isolation they experience in raising ADHD children. One of the reasons they are homebound is because of the difficulty in finding child care for their ADHD children. Providing specific training for child care providers as well as setting up a respite network may help to alleviate some of the isolation that these parents describe.

A few families described having a support network. This often included direct services such as tutoring and activities for the ADHD child. It also provided services for the family through relief care. The families who did describe these programs were participating in the Managing Resources of Montana (MRM) program. This is a state supported, community-based program for assisting families with emotionally disturbed children. Having similar programs for parents who do not qualify for MRM may reduce the impact of ADHD upon the family.

Parents described counseling as more helpful when the counselor was knowledgeable about ADHD and its impact. It may be helpful for counselors to gain specific information about ADHD and the impact on the child and family. It would also be useful if a list of counselors who had received this information were made available to parents.

mothers with support system outside the family showed more improvement.

It may be useful to examine other coping strategies that parents with ADHD children have used. However, it may also be necessary to realize that in spite of engaging in a variety of coping techniques, parenting a child with ADHD may continue to be stressful. Although many parents and ADHD children do learn to cope more effectively as time progresses there are no known cures for ADHD.

Several parents described difficulties with teachers following IEP's and 504 plans. Bringing an advocate to IEP meetings may be beneficial.

Counseling was described as helpful when the counselor was knowledgable about ADHD. Families may find counseling helpful in learning the best ways to handle the child, to understand and handle one's own emotions, and to deal with relations with others. One area that may need special attention is the discussion and agreement between spouses regarding discipline for the ADHD child.

It may be helpful for the entire family, including the extended family, to be involved in education regarding ADHD. To further assist parents to develop convergent views about what ADHD is and what kinds of modifications will be necessary it may also be useful for both parents to attend IEP meetings, evaluations with the doctor, and support group meetings.

Due to the additional supervision required for an extended period of time when parenting an ADHD child it may be critical to obtain respite care for time alone as well as quality time with other children in the family and one's spouse.

Researchers

This study examined the perceptions of parents regarding the impact of ADHD behavior upon their families. In each case only one parent was interviewed. Interviewing all members of the family could provide additional information.

The marriages of those participating in this study were generally described as being impacted by having a child with ADHD. However, most of the participants were mothers. Examining fathers' perceptions regarding the impact of ADHD upon marriages would be useful. It would also be helpful to interview couples to see if they share common perceptions.

Although this study examined the impact of ADHD upon siblings, it was from the point of view of their parents. Interviewing siblings and observing sibling interactions with their ADHD brother or sister would provide additional information. Examining the viewpoints of siblings at different ages may also provide new insights. Exploring how siblings' cope would also be useful.

It is important to continue to analyze effective ways that families cope with ADHD. There has been some previous

> showed stock film of people scrambling for bottled water, canned food, blankets, right before hurricane Hugo hit so many years ago. All I could think when I read this first paragraph and Kelly's statement that, "So many things do center around making sure John doesn't have a problem" was that being a parent of a child with ADHD is like preparing for a major storm or hurricane. You are in a constant alert, grabbing whatever supplies (toys, books, anything) you think will help in the next few hours or days, and not thinking much further ahead than that, because the situation just doesn't allow it. (Alison Boyer, personal communication, July 1996)

Although I did not design the interviews to be therapeutic, several participants expressed the gratitude they felt in having someone who would listen to them. The research also impacted me. Through the research I have gained new understandings about my own ADHD children and our family life. In addition, I have learned and am using new coping strategies.

This study has shared the perspectives, insights, and stories of parents who have ADHD children. Although, the findings were consistent with previous knowledge, this study went beyond what we knew about high stress in these families to examine the characteristics of these specific stressors. It also examined the techniques that the participating families used to cope. However, even though the families described using a variety of coping techniques they still stated that parenting an ADHD child had an impact on most areas of their lives. If one were to use an analogy to describe this we might think of parenting as a roller coaster. There are ups and downs, unexpected turns, some

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APPENDICES

APPENDIX A

LETTER FROM READER

September 17,1996

To readers of this dissertation:

in reviewing transcripts from the three focus group interviews, I found that the interviews were conducted in a naturalistic, conversational way with most of the topics emerging from the participants. After examining the questions and comments made by Julie, I found that ninety three percent of the questions and comments were neutral. Three nonneutral comments were made in focus group one, two in focus group two, and two in focus group three. In each case these were made as a response or clarification to what a participant had previously stated. For example, a participant was describing difficult behaviors that her daughter exhibited in the mornings and Julie questioned, "Because the medicine isn't in her system yet?" In five cases after Julie made the nonneutral comment the participant either totally or partially disagreed. In two cases the participant agreed with the comment. Therefore I found that these comments did not have a great impact on the responses.

I also analyzed all the transcripts from one case study. In reviewing 55 pages of single spaced transcripts I found that Julie asked questions or made comments 169 times. Only one of these was a nonneutral comment.

When using a non-directive approach to interviews rather than a directive approach using standardized questions, there is a serious danger of imposing one's own views, expectations or biases on the focus group. Julie made so few of these percentage wise that I found her detachment quite remarkable.

Sincerely,

Eve Malo

APPENDIX B

SCREENER QUESTIONNAIRE

Hello, my name is Julie Bullard and I am a doctorate student who is conducting research on ADHD. I am also a parent of ADHD children. gave me your name and said that you also have a child between the ages of six and twelve who has ADHD. I am looking for parents that are willing to participate in a two hour focus group or group interview with three to five other parents to discuss the impact ADHD has upon your family. The interviews will be audiotaped so that I can accurately portray the information that is given. However, you and your child's names as well as any other identifying data will be kept confidential. This information will be part of my dissertation and may be part of future articles or presentations. I hope that this information will benefit other families with ADHD children and those professionals who work with ADHD families. Would you be interested in participating in the focus group if you met the research sample criteria and the date and time were convenient for you?

A specific sample of ADHD parents will be chosen for this research project. Those participating must meet the following criteria.

1) Determination of ADHD by a physician, based upon information from a variety of sources including parent and teacher ratings, interviews, neurological exam, physical, child and family history.
2) An ADHD child between the ages of six and twelve.
3) The use of medication to mitigate the symptoms of ADHD.
4) Diagnosis and treatment of the disorder with medication for at least two years.
5) The absence of any major life change within the family during the previous six months including death, long term hospitalization, or divorce.
6) Absence of obvious or known severe physical or emotional disabilities in the child or parents.

Do you meet these criteria?

What day of the week and time of day would be most convenient for you to meet?

Describe what impact ADHD has upon the child's relationships with others in the family.
- siblings
- parents
- extended family

What has been your experience with schools?

Describe the impact that ADHD has upon your relationship with other people.
- spouse
- neighbors
- extended family
- other children in the family

Describe the impact of ADHD on the way that you parent your child.
- discipline
- rules
- supervision

Describe the impact of ADHD on household routines.

Have your goals changed as a result of ADHD? How?
- child
- self
- family

How has ADHD personally impacted you?
- beliefs about parenting
- self concept
- stress

Describe a time that you felt stressed in relation to parenting your ADHD child.
- how experienced the stress
  - physical, thoughts, feelings
- is this the typical way that you experience stress
- indicators that you are stressed

If you were to rate your stress level on a scale of 1-10 with 10 being the most stressful, how would you rate your current level of stress?

Coping strategies employed by the family

Describe what you do to cope with the stress relating to the behavior of your ADHD child.

- adaptations
- stress reducers
- support groups/counseling

AUTHORIZATION: I have read the above and understand the inconvenience of this study.

I,_____ agree to participate in this research. I understand that I may later refuse to participate, and that I may withdraw from the study at any time. I have received a copy of this consent form for my own records.

Signed

_____

Participant

_____

Investigator

_____

Date