

ABSTRACT

PARENTS' PERCEPTIONS OF ASSESSMENT AND TREATMENT OPTIONS FOR THEIR CHILD WITH ATTENTION DEFICIT HYPERACTIVITY DISORDER

By Carla Wech

Assessment and evaluation of attention deficit hyperactivity disorder (ADHD) is a common complaint in primary care. Although, there are ADHD criteria, assessment, and treatment guidelines available to help diagnose a patient, there is variation in the way healthcare providers apply these criteria and guidelines. Medications are often prescribed as a treatment option. It is unknown if other treatment options are offered. Few studies exist on parents' perceptions of assessment and treatment options for their child with ADHD.

The purpose of this study was to determine parents' perceptions of the assessment and treatment options for their child diagnosed with ADHD. The theoretical framework used in this study was McCubbin, Thompson, and McCubbin's Resiliency Model of Family Stress, Coping, Adjustment and Adaptation.

A descriptive survey design was utilized. The setting was a Midwestern suburban clinic of family practice providers. A convenience sample of 59 parents, 18 years of age and older was obtained from the Midwestern clinic, through a computer generated list of children who were diagnosed with ADHD and were being treated in the clinic. Three instruments were used for data collection: the Child Demographic Questionnaire, the Adult (parent) Demographic Questionnaire, and the Parents' Perception Instrument (PPI), which also comprised one open-ended question. Data were analyzed using descriptive statistics.

Results indicated that 57% of parents sought a primary care setting for initial treatment of their child with behavioral symptoms. Ninety-two percent of parents perceived that treatment with medication was helpful. Eighty-five percent of children were managed in the primary care setting, even if they were diagnosed in a psychiatric setting. Eighty-five percent of the parents expressed a desire to learn more about ADHD. The results from the open-ended question on the survey indicated that although parents reported they understood ADHD, they indicated a desire to learn more about other treatment options besides medication, learn techniques to communicate with their child, and strategies to discipline their child.

By understanding parents' perceptions, the advanced practice nurse can identify parental lack of knowledge about ADHD, educate the family, and assist with offering interventions that would help the family adjust, cope, and deal with this diagnosis. With more ADHD being managed in a primary care setting, it is imperative that advanced practice nurse be prepared and knowledgeable about the assessment and treatment options to work with the family.

PARENTS' PERCEPTIONS OF ASSESSMENT AND TREATMENT OPTIONS FOR
THEIR CHILD WITH ATTENTION DEFICIT HYPERACTIVITY DISORDER

by

Carla Wech

A Clinical Paper Submitted
In Partial Fulfillment of the Requirements
For the Degree of

Master of Science in Nursing

Family Nurse Practitioner

at

University of Wisconsin Oshkosh
Oshkosh, Wisconsin 54901-8621

May 2011

APPROVAL

Jayalokshini Sundarajan Advisor

5-10-11 Date Approved

PROVOST
AND VICE CHANCELLOR

Jan R. K...

5/10/11
Date Approved

FORMAT APPROVAL

Marci Nondorf

4/25/11
Date Approved

I would like to dedicate this to my family. I started on this journey to make more of a life for all of us. There were countless times I know I was not there for you, and I hope that you each recognize that hard work and sacrifice will help you attain your goals; It is worth it. I thank God for having a plan for me and steering me down this path to become a nurse practitioner.

To my husband, Dave, you were always there with emotional support, encouragement, and love. You did so many nice things for me. I did this for our future together. To our kids: Stephanie, who was my computer ally, you will make an awesome teacher. To Emily, who was my cheerleader and wishing me "good luck" on my tests. Something so small always meant so much. You have so much to offer. Believe in yourself! To Matthew, you are such a good listener; so patient and understanding if I missed your games because of school work. You helped around the house more than you needed to for your age. I am so proud of you Matthew. Thank you. It was a team effort. I love you all so much. Love, Mom.

To my parents, June and Lyle, I would like to thank you for listening and for your emotional support. I am so lucky to still have my mom and dad. I have loved being a nurse and am so thankful for this awesome career. Thank you.

To my sister, Linda, who helped support and encourage me these last 8 months. Thank you for the countless phone calls and words of wisdom to stay focused. I appreciate the time you took to edit my paper several times near the end. Thank you very much, Linda.

To my sister, Laurie, who helped me edit papers and sent words of kindness and cards at just the right moments. To my sister, Cheryl, who always had a smile and encouraged me. Sisters are special friends. Thank you.

To Lois and Bob, my in-laws, they encouraged me to keep learning. Let's celebrate. Thank you everyone. I am so blessed with a beautiful family.

ACKNOWLEDGMENTS

Thank you to my friends, Tiffany Laughlin-Jones, Mandy Woulf, Amy Schroeder, Anne Swanson, and Annie Peterson. I am so fortunate to have met such wonderful women that are strong, intelligent, and compassionate, and have become dear friends. You each are going to be great nurse practitioners. To a lifetime ahead of us! Thank you.

I would like to thank Dr. Loren Fuglestad. You have been a role model in delivering quality care, treating people with respect and kindness, and being humble. I admired how you could keep your family so important when you are such a busy man. Thank you for your friendship and helping me with clinical hours. I will miss working with you.

I would like to thank Judy Ludack, my manager, who was very understanding and supportive. I appreciate the flexibility you gave me with my work schedule to incorporate continued education and for believing in me. Thank you to Dr. Joyce McCollum for your wisdom and encouragement. You are such an inspiration to be a lifelong student.

Thank you to Dr. Jaya Jambunathan. You are patient in watching a novice write research. You are amazing with how you make it look so easy. I value needing research in my future practice because of what I have learned from you.

Thank you to Dr. Judith Westphal. I have respected your leadership style and experiences in the working world of healthcare. Thank you for leaving a profession that paid you more money so you could plant leadership seeds. You have instilled in me that we can make a difference in this profession of advanced practice nursing through policy. Thank you for conveying empathy and support; the nurse is embraced within you. Thank you.

TABLE OF CONTENTS

	Page
LIST OF TABLES	vi
LIST OF FIGURES	vii
CHAPTER I – INTRODUCTION	1
Significance for Primary Care	8
Statement of the Problem	9
Purpose of the Study	10
Research Question	10
Definition of Terms.....	10
Conceptual Definitions	10
Operational Definitions	11
Assumptions	12
Summary	12
CHAPTER II – THEORETICAL FRAMEWORK AND LITERATURE REVIEW	14
Theoretical Framework	14
Case Study	16
Review of Literature	19
Interpersonal Relationships	19
Structure and Function of the Family	21
Development and Well Being	23
Community Relationships	26
Summary	28
CHAPTER III – METHODOLOGY	29
Design of the Study	29
Population, Sample, and Setting	29
Data Collection Instruments	30
Data Collection Procedure	31
Data Analysis Procedures	33
Limitations of the Methodology and Study	33
Summary	34

TABLE OF CONTENTS (Continued)

	Page
CHAPTER IV – RESULTS AND DISCUSSION	35
Demographic Characteristics	36
Results and Discussion	38
Summary	46
CHAPTER V – SUMMARY, CONCLUSIONS, RECOMMENDATIONS, AND IMPLICATIONS	47
Summary	47
Conclusions Based on Results of the Study	48
Implications for Practice	49
Implications for Education	51
Implications for Administration	51
Recommendations for Further Research	52
Summary	52
APPENDICES	
Appendix A. Resiliency Model	54
Appendix B. Child Demographic Questionnaire	56
Appendix C. Adult Demographic Questionnaire	58
Appendix D. Parents’ Perception Instrument (PPI) for ADHD	61
Appendix E. Child Assent Form for ages 10 – 12	64
Appendix F. Child Assent for Ages 13 – Under 18	66
Appendix G. University of Wisconsin Oshkosh IRB Approval	68
Appendix H. Health Care System IRB Approval	70
Appendix I. Clinic Site Approval Letter	72
Appendix J. Introductory Letter to Participants and Informed Consent	74
Appendix K. American Psychiatric DSM-IV-TR ADHD Criteria	77
Appendix L. Behavior Examples of a Child with ADHD	80
REFERENCES	82

LIST OF TABLES

	Page
Table 1. Parent Demographics	37
Table 2. Child's Demographics	41

LIST OF FIGURES

	Page
Figure 1. McCubbin, Thompson & McCubbin's Resiliency Model of Family Stress, Coping, Adjustment, and Adaptation	18
Figure 2. Management of ADHD	39
Figure 3. Treatment Options Presented to Family	40
Figure 4. Extra-Curricular Involvement	42
Figure 5. Education Evaluation	43

Chapter I

Introduction

Attention deficit hyperactivity disorder (ADHD) is the most common diagnosed neurobehavioral disorder of childhood (Vissers, Bitsko, Danielson, Perou, & Blumberg, 2010). It is characterized by inattentiveness, impulsivity, and hyperactivity. Diagnosis of ADHD can occur as early as 3 years old, with the average age of diagnosis between 8 and 9 years of age (DeNisco, Tiago & Kravitz, 2005). As of 2007, in the United States, ADHD is present in approximately 9.5% children 4 to 17 years of age, affecting boys more commonly than girls (13.2% versus 5.6%); with the national prevalence increasing from 2003 to 2007 annually by 5.5% (Vissers et al., 2010). Attention deficit hyperactivity disorder makes it important for healthcare providers (HCPs) in primary care to be knowledgeable of the criteria to assess and diagnose ADHD (Morley, 2010). Attention deficit hyperactivity disorder affects all races and has been studied in countries such as Iran, Taiwan, the Netherlands, and Australia.

The American Psychiatric Association Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) [American Psychiatric Association (APA), 2000] also recognized ADHD as a mental disorder and has criteria for clinical assessment since the 1970's. Attention deficit hyperactivity disorder is clinically diagnosed and treated in the primary care and behavioral health setting. In 2000, the American Academy of Pediatrics (AAP) established guidelines for the diagnosis and evaluation of attention deficit hyperactivity disorder. The American Academy of Child and Adolescent Psychiatry (AACAP) also has guidelines for ADHD that were developed in 1997 (Bussing & Gary, 2001), which are available on the Agency for Healthcare and Research

Quality (AHRQ) website. The AHRQ is a governing agency and website that has well-known evidenced based guidelines available to HCPs.

The American Academy of Pediatrics (2000) guidelines provide recommendations for the diagnosis and evaluation of the child with ADHD. These guidelines are for primary care clinicians use and include:

1. In a child who presents with inattention, hyperactivity, impulsivity, academic underachievement, or behavior problems, primary care clinicians should initiate an evaluation for ADHD.
2. The diagnosis of ADHD requires that a child meet DSM-IV-TR criteria.
3. The assessment of ADHD requires evidence directly obtained from parents or caregivers regarding the core symptoms of ADHD in various settings, the age of onset, duration of symptoms, and degree of functional impairment.
 - a. Use of scales is a clinical option when evaluating children for ADHD.
 - b. Use of broad-band scales is not recommended in the diagnosis of children for ADHD, although they may be useful for other purposes.
4. The assessment of ADHD requires evidence directly obtained from the classroom teacher (or other school professional) regarding the core symptoms of ADHD, the duration of symptoms, the degree of functional impairment and coexisting conditions. A physician should review any reports from a school-based multi-disciplinary evaluation where they exist, which will include assessments from the teacher or other school-based professional.

- a. Use of behavior scales for teachers is a clinical option when diagnosing children for ADHD.
 - b. Use of teacher global questionnaires and rating scales is not recommended in diagnosing children, although they may be useful for other purposes.
5. Evaluation of the child with ADHD should include assessment for coexisting conditions.
 6. Other diagnostic tests are not routinely indicated to establish the diagnosis of ADHD.

The AAP guidelines (2001) for the treatment of ADHD for the school aged child are:

1. Primary care clinicians should establish a management program that recognizes ADHD as a chronic condition.
2. The treating clinician, parents, and the child, in collaboration with school personnel, should specify appropriate target outcomes to guide management.
3. The clinician should recommend stimulant medication and or behavior therapy as appropriate, to improve target outcomes for the children with ADHD.
 - a. For children on stimulants, if one stimulant does not work at the highest feasible dose, the clinician should recommend another.
4. When the selected management for a child with ADHD has not met target outcomes, clinicians should evaluate the original diagnosis, use of all appropriate treatments, adherence to the treatment plan, and presence of coexisting conditions.

5. The clinician should periodically provide a systematic follow up for the child with ADHD. Monitoring should be directed to target outcomes and adverse effects by obtaining specific information from parents, teachers and the child.

Each of these professional agencies has a common goal to encourage HCPs' utilization of evidence based practice. A triad of combining the latest evidence (research), clinical expertise (experience), and client/patient values (shared decision making) is considered evidenced based practice and is a standard for HCPs (Polit & Beck, 2008). Attention deficit hyperactivity disorder can impact children, such as not achieving academic success, dysfunctional interpersonal relationship with family or friends, or a child's self esteem. Most symptoms occur in early childhood and may continue to be symptomatic through adolescence and adult life (AAP, 2000).

Healthcare providers in a primary care setting often are the initial place parents may seek an appointment to discuss their child with ADHD (AAP, 2000). Most of the existing research has been primarily in psychiatric settings. Further research is needed to determine if the findings of prior research can be generalized to the children that are diagnosed and treated in a primary care setting (AAP, 2000). There is a lack of research on the use of the DSM-IV-TR in populations in a pediatric or primary care clinic. It is difficult to obtain adequate response rates from providers, and monetary incentives or web surveys can be time- and money-intensive (Morley, 2010). There is known variation of how providers of primary care and subspecialty utilize the DSM-IV-TR and the AAP diagnosis and evaluation guidelines (AAP, 2000). Do HCPs in a primary care setting assess and treat ADHD according to the AAP guidelines and/or DSM-IV-TR criteria similar to the psychiatric and psychological professions? The current descriptive survey

study was done to explore parents' perceptions of assessment and treatment options for their child with ADHD in a primary care setting.

A cross-sectional descriptive study was done in Iran by Ghanizadeh and Zarei (2010). The purpose of the research was to identify knowledge and attitude of general physicians towards ADHD and how it was managed. A self-reported questionnaire, with good reliability, had been used in the past on teachers and pharmacists, and was piloted on a small number of general physicians. Estimated time of completing the anonymous and voluntary questionnaire was 10 to 15 minutes. Out of 900 physicians, 605 answered the self-reported questionnaire. Forty six percent (46%) of general physicians reported they had adequate knowledge of ADHD. These general physicians reported that ADHD should be managed by a psychiatrist 70% of the time, psychologists 20% of the time, and neurologists 10% of the time. Forty four percent (44%) of these general physicians referred these children without conducting any further assessment; 18% reported they would accept and manage ADHD in follow up care. Sixty nine percent (69%) knew that Ritalin was a stimulant; 51% reported that Ritalin should not be administered for management of ADHD except in severe cases, yet 93% believed Ritalin is used to increase attention and concentration (Ghanizadeh & Zarei, 2010).

During the assessment phase with the child, the HCP can perform a standard history and physical, a neurological examination, family and school assessment, obtain feedback from the school system with an instrument completed by a teacher describing behaviors, obtain any evidence from their school with report cards, and find out the degree of behavior problems and level of impairment in functioning in a social setting (AAP, 2000). Further history taking questions more specifically address impulsivity, inattentiveness, or hyperactivity. If ADHD occurs, at what age did symptoms appear,

duration of symptoms, what settings do these symptoms occur, and how much do the behaviors impair the child's functioning by himself, or with family and friends or social situations? Lab work, brain imaging, and an electroencephalogram are not indicated to aid in diagnosis for ADHD, but may be beneficial to rule out other co morbid diagnosis like brain tumor, epilepsy, thyroid, or anemia issues. Lack of understanding regarding the DSM-IV-TR criteria and AAP diagnosis and evaluation guidelines on ADHD could lead to improper diagnosis and ineffective treatment options (AAP, 2000).

Prescribing medications has been considered the first line of therapy according, to the AACAP guidelines (AHRQ, 2010). Numerous studies have been conducted on treatment options on the different types of stimulants and their effectiveness. A retrospective study on 137 children who had a diagnosis of ADHD was conducted by Miller-Horn et al. (2008). The study examined the efficacy and tolerability of five different ADHD medications. The participants included 109 boys and 28 girls (mean age 10 years). Limitations to the study included, (a) the lack of a placebo group, (b) participant interpretation of physicians related to clinical improvement, and (c) lack of an objective measurement of physical or perceived patient improvement (Miller-Horn et al., 2008). Seventy-eight percent of the children showed improvement with no statistical difference between the medications. Side effects, such as decreased appetite, insomnia, headaches, and tics were most often reported, with 80% reporting one side effect, 17% reporting two side effects, and 2.8% reporting three side effects. The results showed no major differences in medication effectiveness when treating ADHD alone or if there was another co morbid diagnosis (Miller-Horn et al., 2008). Medications appear ineffective in reducing the behavioral symptoms in up to 30% of the cases per Spencer et al. (in Evans, Schultz, & Sadler, 2008).

A longitudinal (14 month) randomized clinical trial study on treatment strategies for ADHD was conducted on 579 children (MTA Cooperative Group [MTACG], 1999). Children 7 to 9 years of age were assigned to one of four groups. All received medication. There were four categories of medication management: (a) intensive behavioral treatment with medication, (b) intensive behavior treatment and community care with medication, (c) standard community care offering mental health services with medication, and (d) medication management by their provider of choice (MTACG, 1999). The results indicated that medication management and the combined group had similar outcomes, but the combined treatment group had a difference in self-development and personal relationships compared to just behavior treatment and community care. The combined group had outcomes with lower medication doses than just medication management alone. Side effects of medications were monitored monthly. Thirty five percent reported no side effects; 49% reported mild side effects, 11% reported moderate side effects, and 2.9% reported severe side effects. Some of the side effects were listed as depression, worrying, and irritability, which could also be related to situational or environmental concerns (MTACG, 1999). Although this study was completed a decade ago, the MTACG concluded that all four categories of treatment options showed reduction in symptoms. The authors also reported that combined treatment and medication treatment alone were clinically and statistically better at reducing ADHD symptoms. The combined treatment options resulted with the children being on lower medication doses than used in medication management alone (MTACG).

Evans et al. (2008) stated that an alternative treatment option for ADHD was behavior modification, which included working with the child, parents, and teachers on how to help the child with techniques to effectively communicate and interact with the

child. Children with ADHD respond well to clear and consistent behavioral expectations, which can be employed by using rewards and consequences to help mold the child with behaviors that are appropriate and help the child stay in control. Positive and negative reinforcement increase the rate, intensity, or duration of behaviors. Evans et al. recommended that an important element of this process is working with parents to help them identify realistic expectations of their child's behaviors. Another technique was to use daily behavior report cards, an effective communication technique between the school personnel and the child's family. The family reviews the behavior report card with the child each evening and determines what would be appropriate privileges or consequences for the rest of the evening based on the behavior card (Evans et al., 2008).

Evans et al. (2008) recommended parent training is another treatment option for ADHD, a technique that works directly with the child's parents. Parent training teaches the parent skills on how to manage their child's behaviors and involves multiple sessions. An example of a skill was incorporating organization into the parent's life, and the child would also benefit from this. Psychotherapy was another treatment option used to treat ADHD and include social skills training or individual counseling, but is less effective (Evans et al., 2008). There has been a lack of research on other treatment options for ADHD.

Significance for Primary Care

The current study has significance for HCPs, since the findings from understanding parents' perceptions can identify areas for educating parents of children with ADHD. Since most research on the DSM-IV-TR criteria has been done in a

psychiatric setting, more research is needed to find how the DSM-IV-TR criteria are utilized or can be utilized in family practice setting and primary care setting (AAP, 2000).

Understanding parents' perceptions of ADHD can help the HCP to reflect upon their own practice and identify if they are utilizing and adhering to the DSM-IV-TR criteria and AAP guidelines to make a precise diagnosis and provide appropriate treatment. Understanding parents' perceptions can help the HCP to answer questions parents may have regarding medication safety, side effects, and cost, before initiating medication stimulant therapy (McGuinness, 2008). Parents are concerned about addiction, changes in their child's personality, growth, or behaviors. McGuinness (2008) also stated that the best treatment plan includes help, understanding, and guidance from parents and teachers. Bussing and Gary (2001) stated that some parents were hesitant to proceed with pharmacotherapy regime as a primary therapeutic intervention and needed more guidance and education about ADHD, medications, and treatment options and conveyed a need for thorough ADHD assessments before starting their children on stimulant medications.

There has been more interest in ADHD and discussion in the media pertaining to the assessment and diagnostic process and treatment plan, an area that needs more research (AAP, 2000). There is a need for further research on ADHD in the primary care setting.

Statement of the Problem

It has been noted throughout the literature that ADHD is increasing in prevalence in primary care settings. Research has shown there is variation in the way HCPs utilize the ADHD criteria and guidelines for assessment and treatment options. This current

study identified parents' perceptions of the assessment and treatment options for their child with an ADHD diagnosis.

Purpose of the Study

The purpose of this study was to explore parents' perceptions of assessment and treatment options for their child diagnosed with ADHD. The knowledge gained from understanding parents' perception can assist the HCP to be aware of families' understanding of ADHD and identify areas needed for further education. It can also help HCPs to become more aware of the significance of using the DSM-IV-TR criteria and the AAP diagnosis and evaluation guidelines for attention deficit hyperactivity disorder.

Research Question

What are parents' perceptions of assessment and treatment options for their child diagnosed with ADHD?

Definition of Terms

Conceptual definitions.

Child diagnosed with attention deficit hyperactivity disorder: A boy or girl who is a minor and diagnosed with ADHD. Attention deficit hyperactivity disorder was formerly called attention deficit disorder (ADD). Attention deficit hyperactivity disorder is the newer terminology for this diagnosis. For purposes of this study, ADD and ADHD will be used interchangeably.

Assessment: Obtaining data to make decisions.

Attention deficit hyperactivity disorder: Characterized by core symptoms of: inattentiveness, impulsiveness, and hyperactivity. The child needs to have six or more symptoms of behaviors that are persistent for more than 6 months in at least two different settings, usually before the age of 7, that are not congruent with the developmental stage the child is in according to DSM-IV-TR and by the AAP guidelines (2000). The AAP uses this guidance to make the clinical assessment and diagnosis of ADHD, however, is not meant to be the sole source of decision making.

Parent. A father or mother; one who gives birth to or nurtures and raises a child; or a relative who plays the role of guardian (Meriam Webster Dictionary, n.d.).

Perception: Having comprehension about a concept.

Treatment options: Treatment options that can impact the well being of the child, functionality with close friends and family, decrease behavioral symptoms, and increase their ability to function.

Operational definitions.

Child with attention deficit hyperactivity disorder (ADHD): In this study, ADHD is defined as being any one variety of the three subtypes: ADHD with inattentiveness, ADHD with hyperactivity, or ADHD with impulsivity. Attention deficit hyperactivity disorder can be diagnosed by a psychiatrist, psychologist, or a primary care provider (see Appendix for DSM-IV-TR criteria). This study will limit its focus to a child with ADHD between 3 and 17 years old because the DSM-IV-TR criteria, the AAP diagnosis and evaluation guidelines, and AACAP guidelines are for these age groups. Attention deficit disorder and ADHD will be used interchangeably in the study.

Assessment: Includes a complete history and physical exam, a neurological examination, family and school assessment, developmental history, a chronological

history of the behaviors, the duration and the settings behaviors are exhibited, impairment of functioning, and ruling out any other reason for these behaviors (AAP, 2000).

Parent: A person of legal age over 18 years, male or female, who is the biological parent, the adopted parent, or a stepparent for the child.

Perception: Parents' perceptions as measured by the Parent's Perception Instrument.

Treatment option: An intervention, such as pharmacotherapy (prescribing medication), behavior modification, psychotherapy, or parent training (Bussing & Gary, 2001).

Assumptions

1. Survey instruments are an accurate method to collect data and measure parent's perceptions of assessment and treatment options in this study.
2. The parent will fill out the survey honestly.
3. ADHD affects both the child and family.

Summary

Attention deficit hyperactivity disorder is becoming more commonly diagnosed and prevalent in the primary care and behavioral health setting. The literature reveals a lack of studies done in primary care on ADHD and variation in using the DSM-IV-TR criteria and AAP diagnosis and evaluation guidelines. The purpose of this study was to explore parent's perceptions of assessment and treatment options for their child with an ADHD diagnosis. In this chapter, the background, the significance of the topic as it

relates to advanced practice nursing, the literature review, the purpose and rationale of the study, research questions, conceptual and operational definitions of terms, and assumptions were presented.

Chapter II

Theoretical Framework and Literature Review

The purpose of this study was to explore parent's perceptions of assessment and treatment options for their child diagnosed with ADHD. McCubbin, Thompson, and McCubbin's (1996) Resiliency Model of Family Stress, Coping, Adjustment and Adaptation, was chosen as the theoretical framework to guide this study. A description of the theoretical framework, a case study application of the model, followed by a review of the literature is presented below. The review of literature is divided into four categories 1) interpersonal relationships 2) structure and function, 3) development and well being and 4) community relationships.

Theoretical Framework

McCubbin, Thompson, & McCubbin's Resiliency Model of Family Stress, Coping, Adjustment and Adaptation is applicable to this study because ADHD can be assumed as stressful and can affect the structure and function of the family unit. According to McCleary (2002), ADHD is associated with difficulty with social functioning and adjustment of both the parent and the adolescent. McCubbin, Thompson, & McCubbin's Resiliency Model of Family Stress, Coping, Adjustment and Adaptation describes four areas of family life, and the family unit functions that are affected by stress and strain: (a) interpersonal relationships, (b) structure and function, (c) development and well being, and, (d) community relationships (McCubbin, Thompson, & McCubbin, 1996).

The first category, interpersonal relationships, is defined as how well the child interacts or relates with others like parents, siblings, friends, and teachers. This includes

communication skills, and physically or behaviorally relating to others who have an ADHD diagnosis. Structure and function is the second category and implies how the ADHD child is able to perform and behave in social settings, with and without rules. Development and well being is the third category and indicates how the ADHD child is growing developmentally, physically, cognitively, and spiritually. The fourth category is community relationships. This means how well the child and family interact with others like school personnel, HCPs, church, and clergy, and conversely, how community relationships help the child or family with adjusting or adapting with ADHD.

The model of resiliency fits well with this study because it incorporates the school, family, and HCP communities as partnerships in helping the family adjust and deal with stress. The resiliency model is inductive and has been revised to incorporate more cultural sensitivity. McCubbin et al. (1996) state that the model concepts can help with flexibility and individuality when guiding a patient and their family, with shared decision making regarding an intervention or treatment option. As the HCP understands how the family perceives stress in their life, and understands where the family is in the adjustment and adaptation of functioning, healing can occur as they change and respond (McCubbin et al., 1996). McCubbin et al. also stated that the model concepts can guide health professionals to offer treatment options using those described in the AAP or AACAP treatment guidelines, specific to the needs of families to help them adjust and adapt. Attention deficit hyperactivity disorder affects children at home, at school, with friends, and in the community (McCleary, 2002).

Case Study

Taylor is an 8-year-old boy. He has difficulty sitting at the kitchen table long enough to eat his supper without getting up and going to play with a toy, while he is still chewing. Eating supper becomes a long, drawn-out event, and his mother thinks he is just not behaving. The family dynamics are tense, and there is conflict trying to get Taylor to sit and eat.

At school, Taylor blurts out saying something before the teacher calls on him (impulsive) or he doesn't respond when somebody calls his name or when the teacher is going over an assignment (inattentive). When trying to play with friends, he is constantly switching his toy he is going to play with and cannot just finish one game, or he drops the toy and moves on to the next (hyperactivity). His mother reports that these symptoms were going on since he was 5 years of age, and they happen at home, school, or if he is over at his friend's house. She also mentions that sometimes his behaviors are so unpredictable, she avoids going to public places due to his hyperactivity, inattentiveness, and impulsivity. Other family members have also noticed the behaviors, and grandma suggests to Taylor's mom to take him to the HCP for an evaluation.

Taylor's first appointment is with the HCP. The HCP, the parent, and the child discuss the child's behaviors in different settings, including how the child is doing academically. The mom then fills out a questionnaire about behaviors seen in her child and shares the paperwork from the school teachers describing behaviors and attention span with the healthcare provider. The HCP reviews the history and does a physical exam. The HCP has completed a thorough family, medical, and social history, including school dynamics, and reviewed the prenatal and developmental milestones thus far for

the child. The HCP performs a physical and neurological examination to rule out physical reasons for the child's behavior. The HCP decides that no lab work is needed and concludes there is no physical reason for the behavioral symptoms. The HCP discusses the findings with the family and gives the clinical diagnosis of attention deficit hyperactivity disorder. The HCP proceeds to educate and explain potential treatment options, such as behavior modification, parent training, psychotherapy, pharmacotherapy, or a combination of these options. The HCP does not find out the parents' perceptions of ADHD. The case study demonstrates how the symptoms or a diagnosis can affect the family, the child's development, the family structure and functioning, the interpersonal relationships and the community relationships with school.

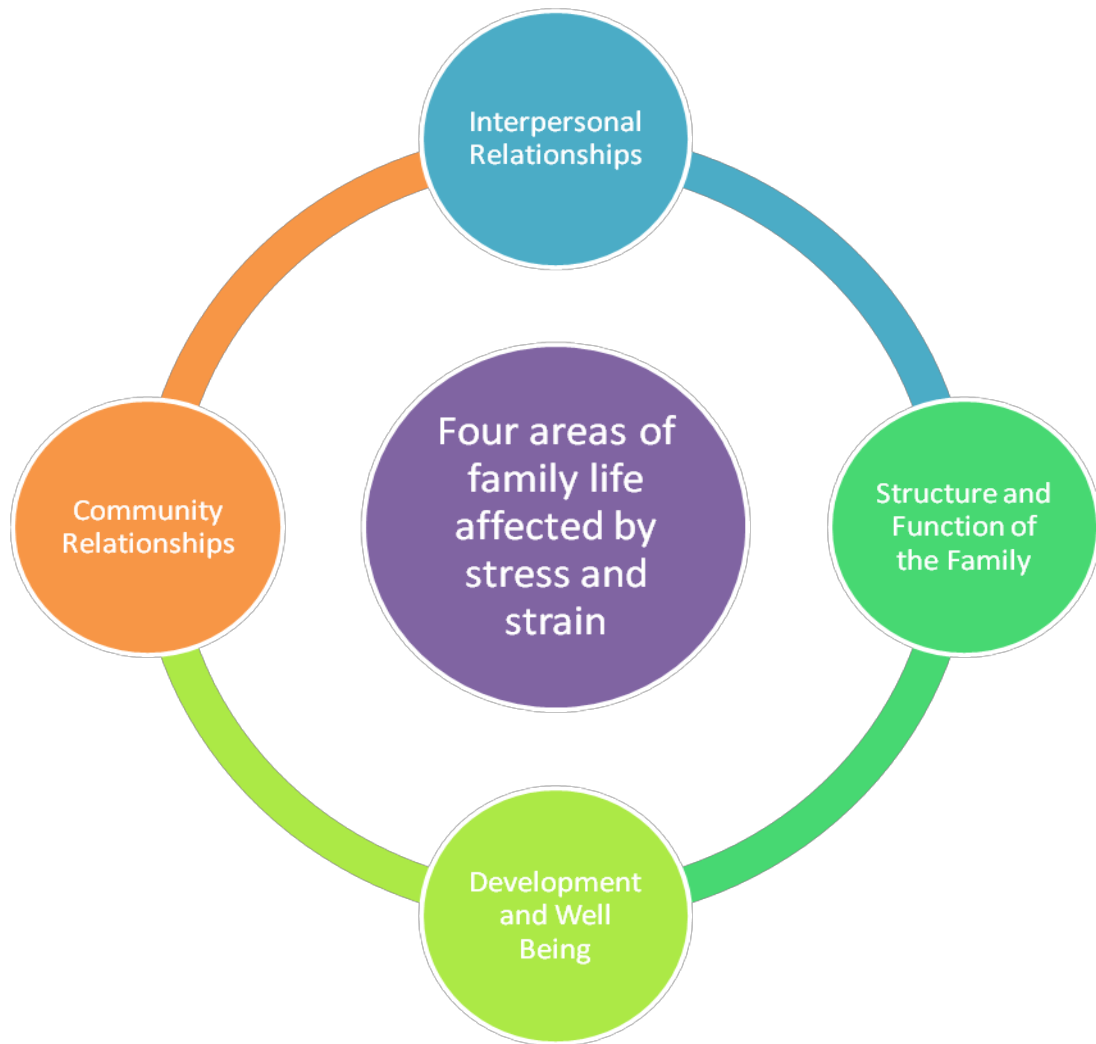


Figure 1. McCubbin, Thompson & McCubbin's Resiliency Model of Family Stress, Coping, Adjustment, and Adaptation (1996)

Review of Literature

The review of literature was categorized using the Resiliency model framework: (a) interpersonal relationships, (b) structure and function of the family, (c) development and well being, and (d) community relationships.

Attention deficit hyperactivity disorder is a recognized psychiatric disorder (APA, 2000), with specific criteria of how to diagnose clinically, which are the behavioral symptoms of inattentiveness, hyperactivity, or impulsivity, which need to persist for at least 6 months and must be in at least two different settings. Symptoms are usually present before age 7 years to a degree that is not normal behavior for the child's developmental level and age (Saadah & Saadah, 2004).

Interpersonal relationships.

Attention deficit hyperactivity disorder has social implications on the child and affects relationships with the parents, other family members, school personnel, and friends, and also affects their self esteem (Salmeron, 2009). A cross sectional study was conducted by Klassen, Miller, and Fine (2004) in a clinic setting in Canada on 165 children diagnosed with ADHD, with a mean age of 10 years. The author studied health related quality of life (HRQL) of children with ADHD compared to those without ADHD or other co morbid diagnosis. The author utilized a 50-item parent version of the Child Health Questionnaire to measure physical and psychosocial health. The findings indicated that parents reported that the child with ADHD had more problems with behavior, emotions, and self esteem. Parents also reported that ADHD impacted the parents' mental health and their time to get their needs met, and interfered with family togetherness and family planned activities (Klassen et al., 2004).

A qualitative study was done on a purposive sample of 27 (11 men and 16 women) young adults ages 18 years to 25 years who attended one of four post secondary education settings (Waite & Tran, 2009), to see if there were any repercussions for the study participants, as they were young adults after they had been treated with ADHD medications. The authors wanted to determine some of the help-seeking behaviors for ADHD among adults from a diverse ethnic background in a postsecondary setting. The inclusion criteria to participate were: (a) confirmed diagnosis of ADHD by a licensed healthcare provider, (b) currently 18 years or older, (c) spoke English, and (d) had identified self as an ethnic minority. Participants were paid \$20 and \$10 respectively for participating in the study. In-depth interviewing and directed qualitative content analysis was used. The demographic survey captured age of diagnosis, current age, provider that diagnosed (physician or psychologist), current age, age at diagnosis, and any psychiatric co morbidities. The young men in the group offered biomedical and genetic reasoning for their ADHD (Waite & Tran, 2009)). The girls were more inclined to equate their ADHD from their environment or too strong or too weak parenting and some genetic aspects, as well. Other findings from this study were: having internal chaos; lacking employment stability, and reporting concerns with personal relationships and friendships. The participants reported a desire to own their own business, so they could go by their own rules rather than follow rules of an employer. Two-thirds of the participants had been diagnosed in their later teen years, and over one-half of the group was diagnosed by their physician or psychologist (Waite & Tran, 2009).

Most young adults did not access support services through the campus student disability due to not identifying themselves as having a disability, were unaware of

services offered, and made personal choices not to use the services because of an ADHD diagnosis and having a stigma attached for using the services (Waite & Tran, 2009). Many of the students reported that not having knowledge about ADHD early on and life skills to learn self acceptance and self control would have given them more capabilities to deal with situations. The young adults reported having other emotional symptoms in addition to ADHD, like depression, anxiety, substance abuse, worry, or an eating disorder. Many tried pharmacology as a treatment and reported that the medications helped with some symptoms but did not eliminate all symptoms (Waite & Tran, 2009).

Structure and function of the family.

According to Riley et al., (2006), the Family Strain Index (FSI) was used in a European study of 1,478 children; 1,477 parents completed the survey. The FSI was used to measure two aspects of stress and strain on the family dealing with ADHD. The results indicated over half of the families indicated stress or worry in the prior 4 weeks. Almost 75% of the families reported their child caused tension or conflict in the family, and almost 40% reported being interrupted during their leisure/relaxation time, affecting the structure and function of the family unit (Riley et al., 2006). The authors concluded that ADHD can result in functional impairment in academic, family, and social settings.

Bussing and Gary (2001) conducted an exploratory descriptive study on potential variation between treatment recommendations in professional practice guidelines for ADHD and treatment preferences by the parent of the child with ADHD. Sample size was 24 families from a single school district. The research evaluated parental treatment approaches to ADHD and compared parents' evaluations with the guidelines for ADHD from professional organizations. The average age of the child was 9.5 years, and 64%

of them were boys. Sixty percent received special education services in the school for academic difficulties, and 40% received special education for emotional services. All 25 children met the criteria for ADHD according to DSM-IV (2000), and half of the children came from single parent families. The results from this study revealed that parents had utilized a variety of home remedies, ranging from behavior modification and religion, to diet, vitamins, and stimulant therapy. Parents also conveyed a need for thorough ADHD assessments before starting their children on stimulant medications. Some parents were hesitant to begin and be compliant with a medication regime as a primary therapeutic intervention and needed more guidance and education about ADHD, medications and treatment options (Bussing & Gary, 2001).

A pseudo randomized, multiple blind, placebo controlled, crossover medication design was conducted over 10 weeks by Van der Oord, Prins, Oosterlaan, and Emmelkamp (2007). There were 50 children in the study, but through attrition, the final groups consisted of 21 children in the medication only (methylphenidate) group and 24 children in the combined treatment group (methylphenidate and multimodal treatment). The group with multimodal behavior therapy consisted of child and parent behavioral therapy and a teacher behavioral training, in addition to taking medication for ADHD. The effects of methylphenidate were monitored daily at school by teachers and daily at home with parents. The authors used Conner, Loney and Milich's scale to assess ADHD symptoms, and Mcburnett et al.'s scale to assess impairment (in Van der Oord, et al., 2007). Limitations were the small number in each group, which limited the statistical power. The findings showed no evidence that there was further benefit by adding multimodal treatment to the stimulant treatment (Van der Oord, 2007).

Gau (2007) did a study in Taiwan on 375 children (mean age of 10 years) who were being treated with methylphenidate. The author looked at ADHD and its alterations in family dynamics, such as the stress level of the mother, parenting styles, and dysfunctional interaction between the child and parent(s). Gau concluded that more boys than girls have ADHD and that mothers of children with ADHD were more anxious, depressed, less affectionate, more controlling, and overprotective in their parenting style. Children who were medicated had more impaired parental and family dysfunction in Taiwan. The author stated that other treatment options might be necessary in helping families deal with behavioral concerns of the child and improve relationships in the family (Gau, 2007).

Development and well being.

There are multiple projected etiologies for ADHD and none are absolutely confirmed. Arnsten (2006) reported that theories of ADHD could be a combination of genetic factors and the environment affecting the prefrontal lobe cortex, which is needed to regulate the behavior and affect inadequate levels of behavior. Mick, Biederman, Faraone, Sayer, and Kleinman (2002) found that there was a double increased risk of having ADHD if children were exposed to maternal smoke and alcohol during pregnancy. Wilens et al. (2005) found there was an elevated risk of ADHD if the children's parents had substance abuse problems or if the parents had a history of ADHD, implying a genetic component to etiology of ADHD in the development and well being of the child.

Children who were diagnosed with ADHD had a higher risk of psychiatric co morbid diagnosis, such as oppositional defiant disorder, conduct disorder, and mood disorders (Miller-Horn et al., 2008). If these children were not treated it could affect their

well being and development, resulting in lack of academic recognition, poor interpersonal relationships, low self esteem, and increased incidence of substance abuse (Miller-Horn et al., 2008). According to McCleary (2002), ADHD is associated with difficulty with social functioning and adjustment of both the parent and the adolescent.

Although medications are often prescribed as a first line intervention for ADHD, there is no consensus of an objective way to measure the effectiveness of the medications. A double blind, placebo controlled, crossover study was done by Pollak, Shomaly, Weiss, Rizzo, and Gross-Tsur (2010). The objective of the study was to assess the ability of the virtual reality classroom to quantify the effect of pharmacological treatment of methylphenidate (MPH) in ADHD 1 hour post-MPH or 1 hour post-placebo. There were 27 children (sixteen boys and 11 girls) ages 11 years to 17 years. Exclusion criteria were history or diagnosis of serious systemic or neurological condition, severe visual impairment, major developmental disorder, or psychotic disorder. Of the 26 participants, seven were already taking MPH and 19 were newly diagnosed by a child neurologist at the neuro-pediatric unit. The test consisted of continuous performance tasks (CPTs), which were administered for 10 minutes and had audio distracters. Two instruments were used. The first was the ADHD rating scale assessing 18 individual criteria symptoms on a rating scale. This instrument had an internal consistency of 0.86 to 0.92. The second instrument was a subjective feedback questionnaire, which consisted of eight items assessing the participant's subjective feelings during a testing session. This instrument had a reliability of 0.70 to 0.81. The findings were that CPT was a user-friendly way to evaluate subjects with ADHD and was perceived as enjoyable

to complete. Additionally, the MPH had a positive effect by decreasing reaction time and had fewer omissions with increased attention time (Pollak et al., 2010).

The gold standard for treatment for ADD/ADHD is pharmacotherapy with stimulants (Magill, 2009). This does not mean that the parents will be ready for and choose pharmacotherapy as the option for treatment. The HCP should offer alternative therapies alone or in addition to pharmacotherapy, to see how the family chooses to learn to adjust and adapt and be resilient with the ADD diagnosis (Magill, 2009). Treatment options for ADHD can impact the interpersonal relationships, structure and function, development and well being of the child, and community relationships.

A 14-month randomized clinical trial of treatment strategies for ADHD showed medication to reduce negative peer interactions dramatically (MTACG, 1999). Results from that clinical trial indicated a need for a lower total daily dose of stimulant medication when combined with other treatment alternative options (MTACG, 1999). In 2006, the Federal Drug Agency (FDA) proposed a 'black box warning' describing the cardiovascular risks of stimulant drugs. This warning was not put into action, and instead, the FDA advised manufacturers of ADHD medications to change product labeling to advise patients of potential side effects (McCarthy, Cranswick, Potts, & Wong, 2009). In 2008, the American Heart Association (AHA) recommended cardiovascular monitoring of children and adolescents with ADHD. The AHA further recommended a complete history by HCPs, to include a review of family history of cardiac disease, unexplained or sudden death, personal history, medication history, baseline blood pressure and pulse, and thorough physical exam, adding an electrocardiogram (ECG) prior to stimulant therapy (MTACG, 1999). However, the routine use of ECG is not supported by groups such as the AAP (McCarthy et al., 2009).

A retrospective study was done using the United Kingdom General Practice Research Database (GPRD) to identify cases and causes of death in patients prescribed stimulants and atomoxetine to determine if there was any association between the medications and sudden death (McCarthy et al., 2009). The authors followed patients aged 2 years to 21 years from January 1993 to June 2006, from the date of their first prescription and one of the following: date of death, transferred out date, age > 21, or the end of the study. The authors reported seven deaths, which is comparable to one death for every 2,662 being treated with a stimulant in that study. Sudden death was identified as instantaneous death and all deaths occurring within 24 hours of an acute collapse. General practitioners were sent a questionnaire to complete and validate cases and causes of death once a death had been identified. Crude and standardized mortality ratios were calculated on all cases of death. The findings showed there was no increase in the risk of sudden death associated with stimulants or atomoxetine. There was an increase in risk of suicide, yet they could not associate the medications with the suicide because of other factors, such as depression and antisocial behavior, that could have increased the risk factors for suicide (McCarthy et al., 2009).

Community relationships.

Attention deficit hyperactivity disorder also has ramifications in the community, such as the school. Children with ADHD are at a higher risk for school failure, social isolation, and becoming involved with peers that get into mischievous behavior (Biederman & Faraone, 2004). Often it is the teacher who may pick up on behaviors that are out of context for a child of that developmental age and bring this to the attention of the parent. Teachers play a role by interacting and communicating with the family by documenting behaviors on different ADHD screening instruments that can be used as

information in the assessment phase or for follow up of ADHD. One screening instrument is the Conner's Scale for parents and Conner's scale for teachers; these instruments provide subjective feedback before or after being on medications or other alternative therapies and the results can be brought to the physician's office by the child's family (in Biederman & Faraone, 2004). Biederman and Faraone noted that although the Conner's scale was developed by a psychiatrist and used for 30 years, there is no validity to this instrument. No instruments used in primary care reliably assess the nature or degree of functional impairment of a child with ADHD (AAP, 2000). Children with ADHD might need more time and attention because effects of ADHD can cause slower academic progression, increased struggles with reading and comprehension, unorganized, instability with friends, and lower self esteem (Lopez-Munoz, Alamo, Quintero-Gutierrez, and Garcia-Garcia, 2008).

A pilot family-based, controlled study of parents with or without substance use disorders (SUD) and with or without ADHD predicted ADHD in their offspring (Wilens et al., 2005). There were 96 families in the study. The findings from this study indicated that if a parent had substance use disorder and ADHD, there was 50% likelihood their offspring would have ADHD (Wilens et al., 2005). The limitation in the sample came from an outpatient treatment center that did not represent the population of families as well (Wilens et al., 2005).

The review of literature has shown there are guidelines available for the assessment and treatment of a child with ADHD. There has been research on medications, but not much research on the alternative treatment options, such as parent training, behavior therapy, and cognitive training. There is known variation of how healthcare providers utilize the DSM-IV-TR and AAP guidelines. There is little research

done that elicits parents' perceptions about the ADHD assessment and treatment process.

Summary

The purpose of this study was to explore parent's perceptions of assessment and treatment options for their child diagnosed with ADHD. The theoretical framework, case study, and literature review were presented in this chapter. The literature review was categorized within the framework of how ADHD can impact the interpersonal relationships, structure and function, development, and well being of the child, and community relationships. When HCPs understand parents' perceptions, they can help the family adjust and adapt to the ADHD diagnosis. This study was guided by McCubbin, Thompson, and McCubbin's Resiliency Model of Family Stress, Coping, Adjustment and Adaptation theoretical framework.

Chapter III

Methodology

The purpose of this study was to explore parent's perceptions of assessment and treatment options for their child diagnosed with Attention Deficit Hyperactivity Disorder. In this chapter the methodology, including the design, population, sample, setting, data collection instruments, procedures, data analysis, and limitations are addressed.

Design of the Study

A quantitative, descriptive survey research design was used for the study. A descriptive survey method is appropriate for this study because surveys can be an important clinical tool for evaluating the impact of treatment on children with ADHD in the real world setting, as well as parents' perceptions of their child's treatment (Antonucci, Kunins, Manos, Lopez, & Kerney, 2010). The survey method is one technique to obtain information from real life experiences that is difficult to acquire from random clinical trials (Antonucci et al., 2010).

Population, Sample, and Setting

The target population for this study was parents whose children were diagnosed with Attention Deficit Hyperactivity Disorder or Attention Deficit Disorder. Inclusion criteria for parents were: at least 18 years of age, have a child diagnosed with ADD or ADHD, speak English, and willingness to participate. Parents could be either biological, step-parent, or guardian of the child. Inclusion criteria for children were: between 3 and 17 years of age, a current patient at a primary care clinic, diagnosed with ADHD

according to ICD-9 code of 314.9 or ADD with an ICD-9 code of 314.0, and willing to participate in the survey by providing assent.

The setting was a family practice primary care clinic within a large healthcare system located in a suburban area in the Midwest, with a total panel size of 8,200 patients. This setting was one of 29 family practice clinics in the healthcare system. There were three family practice physicians, one family nurse practitioner, and one internal medicine physician, who cared for people of all ages and races. The internal medicine physician cared for 2,100 patients, ages 18 and older, who did not meet inclusion criteria for the sampling.

Data Collection Instruments

Three instruments were developed and designed by the researcher for data collection. They were created to elicit responses specific to the research question.

- The Parents' Perception Instrument (PPI)
- Child Demographic Questionnaire
- Adult (parent) Demographic Questionnaire.

The first instrument, the PPI (Appendix D), had 10 questions that were either multiple choice or fill-in-the-blank. A qualitative open-ended question was on the PPI and asked participants for suggestions on what to teach parents whose child was newly diagnosed with ADHD. Information from the PPI included: length of time child was diagnosed with ADHD, what was included in the assessment, types of treatments offered, parents' understanding of ADHD, child's response to medications, and the parents' awareness of HCP appointments. The reliability of the PPI was 0.552.

The second instrument, the Child Demographic Questionnaire (Appendix B) consisted of eight questions: gender, age the parent perceived the child had ADHD, age the child was diagnosed with ADHD, who diagnosed the child, and setting where child was evaluated and diagnosed (primary care versus mental health clinic).

The third instrument, the Adult Demographic Questionnaire (Appendix C) consisted of twelve questions concerning the parent: gender, age, marital status, number of adults living in the home, level of education, race, income, and employment and insurance information. These three instruments were appropriate for the study, as it allowed the participant to respond to sensitive questions anonymously and in the privacy of their own home. For the purpose of this study, the child was not requested to fill out a demographic questionnaire nor did the researcher have personal contact or communication with the child.

Data Collection Procedure

The researcher obtained approval for this study from the Institutional Review Board (IRB) at the University of Wisconsin Oshkosh and a Midwest healthcare system. The healthcare system IRB stipulated that (a) the researcher obtain written permission from the clinic manager indicating agreement for the clinic setting and population to be used for this study, and (b) an assent was obtained from children ages 10 years to 12 years; although, children did not fill out any questionnaires. Health Information Portability and Accountability Act (HIPPA) regulations were followed with no patient identifiers, complete anonymity, and no coding done to match a patient to a completed instrument. Parents were informed that participation was voluntary. The parent's and child's identities remained anonymous to the researcher. The researcher explained the

purpose of the study and the necessity for confidentiality and anonymity with the health system clinic manager and office worker who assisted the researcher with data collection.

Subjects were obtained via the clinic manager, who generated a computerized report with the ICD-9 code of 314.9 for Attention Deficit Hyperactivity Disorder and 314.0 for Attention Deficit Disorder. This report included names of all potential children in the sampling frame. The potential sample was further stratified by age to only include children 3 to 17 years of age. Therefore, all potential participants who fulfilled the criteria for the sample selection were included in the mailing.

The clinic manager made computerized address labels that were affixed to the research packet envelope. Research packets were mailed out to a total of 59 participants (parents) who were identified from a computer generated list of children diagnosed with ADHD. The research packet consisted of a participant letter, informed consent, child's assent, and the three instruments. The participant letter explained the purpose of the study, informed consent, and child assent. Only the clinic manager and an office worker were aware of the names on the list, as they affixed the address label to the research packet envelope. This computerized report of the sample with names was kept in a separate locked filing cabinet in the clinic manager's office with no access to the researcher. The list of names was shredded by the clinic manager after data collection was completed.

Research packets were mailed out to the homes of parents of the child diagnosed with ADHD. The research packet consisted of an informational letter to the participant explaining the purpose of the study, the informed consent, the risks and

benefits of participating, and an assent form for children 10 to 12 years of age and children 13 to 18 years of age.

Parents were given instructions on how to complete the instruments in the privacy of their home. Instructions were provided to return the completed instruments in a prepaid envelope addressed to the clinic. Returning the completed instruments implied informed consent.

Instructions were provided in the participant letter to direct questions, if any, regarding this study or the instruments to the researcher, the IRB contact information for the University of Wisconsin Oshkosh, or the IRB for the Midwestern healthcare system. There was no further contact with anyone on the list after the initial mailing. It was explained in the participant letter that the written results of this study would be provided to the primary family practice clinic by Summer 2011.

Data Analysis Procedures

Data were analyzed using descriptive statistics such as averages, frequencies, and percentages (Polit & Beck 2008). Reliability of the Parents' Perception Instrument was 0.55.

Limitations of the Methodology and Study

1. Since the PPI was a researcher developed instrument, there was no established reliability.
2. The survey instrument was not piloted with parents.
3. The size of the sample limited generalization of the findings.
4. This study was limited to one setting and one geographical location.

5. Since the clinic setting was undergoing a major computer software transition just prior to generating the sample report, and patient charts were in the process of being created electronically, not all health history with diagnosis and ICD-9 codes had been recreated, updated, or transferred. This impacted the potential number of participants in the sample.

Summary

A descriptive survey design was used for this study. The purpose of this study was to explore parent's perceptions of assessment and treatment options for their child diagnosed with ADHD. A total of 50 research packets were mailed out to parents of children diagnosed with ADHD. Descriptive statistics were used to analyze the data. In this chapter the methodology, including the study design, the population, sample and setting, study instrument, data collection, procedures, anticipated limitations, and data analysis of this study were presented.

Chapter IV

Results and Discussion

The purpose of this study was to explore parent's perceptions of the assessment and treatment options for their child diagnosed with Attention Deficit Hyperactivity Disorder. In this chapter, the results of the study are described using the Resiliency Model categorized according to interpersonal relationships, development and well being, community relationships, and structure and function of the family.

This study was a descriptive survey that explored parents' perceptions of assessment and treatment options of their child with ADHD. The names of children who met the inclusion criteria were obtained from a sampling frame that was computer-generated at a Midwestern suburban clinic of family practice healthcare providers. The clinic manager created a report using the ICD- 9 code for ADD and ADHD to generate the possible sample. The sample was obtained according to the inclusion criteria for children 3 to 17 years of age. This resulted in a computer generated list of 59 children who were diagnosed with ADHD. Complete anonymity and confidentiality were maintained in mailing out the research packets. The research packet included the child and adult (parent) demographic questionnaires and the PPI. The PPI had a Cronbach alpha of 0.552. The clinic manager mailed out the research packets. For the purpose of this study, the child was not requested to fill out a demographic questionnaire nor did the researcher have personal contact or communication with the child.

Fourteen completed questionnaires were returned from parents for a 23% response rate. The returned questionnaires were kept locked in a cabinet in the clinic

manager's office until the end of the data collection period. The computer-generated list of names was shredded after data collection ended.

Demographic Characteristics

Demographic data indicated that 100% of the parents were White, 78% had commercial insurance, while 21% had Medicaid (see Table 1). This differs from Morbidity and Mortality Weekly Report, where the reported rates of ADHD were noted among multiracial children (14.2%) and children insured by Medicaid (13.6%) (Vissers et al., 2010). The results of this study must be interpreted with caution because of the small sample size.

Thirty-five percent of the participants had an annual income of less than \$35,000; and 50% of the participants had income of \$65,000 or more a year. Sixty four percent of the participants worked full time. Eighty five percent of the parents were older than 35 years of age. The educational level of the parents was split at 50% of the participants being high school or vocational technical school level and 50% of the participants having bachelors or masters degree. Fifty percent of the sample was from a rural area and 50% were from suburban and urban areas.

Table 1.

Parent Demographics

	Frequency	Percentage
Gender		
Male	1	7.14
Female	13	92.86
Ethnicity		
White	14	100.00
Relationship to Child		
Parent	13	92.86
Guardian	1	7.14
Current Marital Status		
Single	3	21.43
Married	7	50.00
Divorced	3	21.43
Separated	1	7.14
Number of Adults in Home		
1	2	14.29
2	12	85.71
Number of Children in Home		
1	1	7.14
2	8	57.14
3	3	21.43
4	2	14.29
Highest Level of Education		
High School (or equivalent)	4	28.57
Vocational/Technical degree)	3	21.43
Bachelor's Degree	5	35.71
Master's Degree	2	14.29
Family Income		
0 – 19,999	2	14.29
20,000 – 34,999	3	21.43
35,000 – 49,999	1	7.14
50,000 – 64,999	1	7.14
65,000 – 79,999	2	14.29
>80,000	5	35.71
Employment Status		
Full-time	9	64.29
Part-time	3	21.43
Unemployed	1	7.14
Disability	1	7.14
Type of Insurance		
Commercial	11	78.57
Medicaid	3	21.43

Results and Discussion

The results indicated that 92% of the families had an appointment to discuss their child's behavior and symptoms with their doctor or nurse practitioner, 71% filled out a questionnaire about their child's behavior, and 7% of the children had labs drawn in the assessment phase of their child seeking evaluation and treatment. Comparing this study's results to the AAP guidelines, 92% had an initial evaluation face-to-face, as recommended by the AAP and more people in this study filled out a questionnaire about their child's behaviors. However, this researcher was unable to identify if these instruments were utilized in the decision-making process for diagnosis of ADHD. The AAP recommends ADHD questionnaires and instruments should not be used for diagnosing ADHD, but may have other purposes. The results of this study showed utilization of lab in the assessment phase was minimal (7%). The AAP recommends no lab work is needed unless there is an indication from the history and physical obtained.

Forty-two percent were referred to psychiatry or psychology for further evaluation or treatment, 64% were offered additional support and information on ADHD, 100% were offered medications, 20% were offered behavior modification, 20% were offered parent training, and 20% were offered psychotherapy. The findings from this study indicated medications more than behavioral therapy was used, but in alignment with the AAP recommendations to offer stimulants and/or behavior therapy as appropriate. Eighty-six percent had their child's ADHD managed by a family nurse practitioner, family doctor, or pediatrician (see Figure 2). These results differ from the study done by Ghanizadeh and Zarei, (2010), who stated that 5% of the general physicians reported assessing and managing ADHD, and 44% of physicians referred children to psychiatry without doing an assessment.

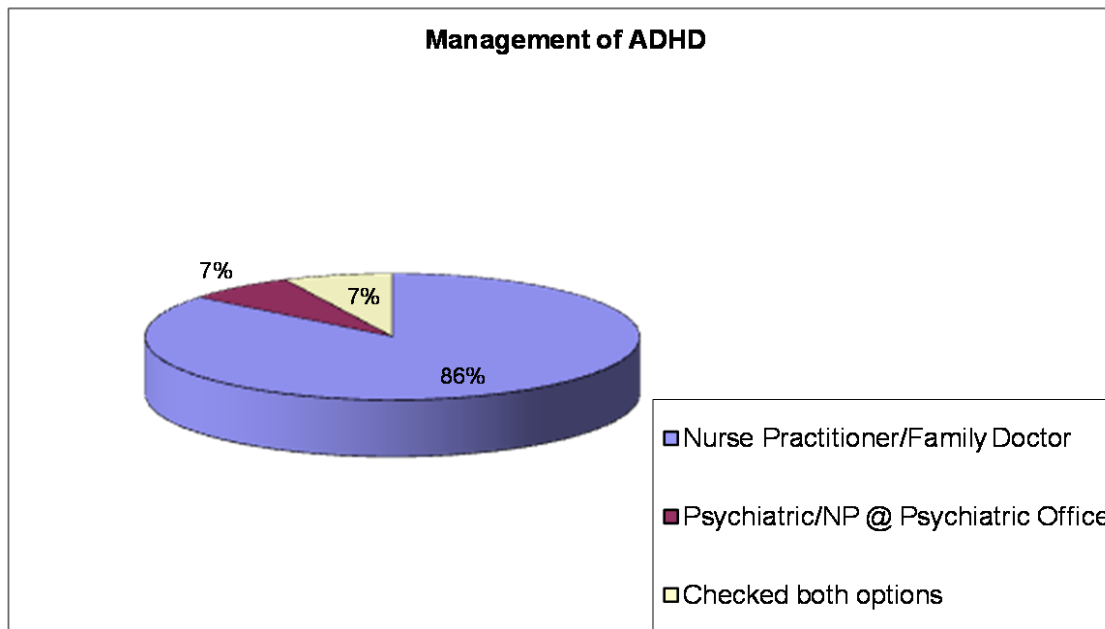


Figure 2. Management of ADHD.

In this study, 100% of the children were offered medications, and 92% of the children were taking medications (see Figure 3). Ninety-two percent of the families believed that the medication was helping their child. The medication dosages for 84% of the children were not changed in the past month. The results of this study indicated a higher medication use (92%) than a study done by McGuinness (2008). Sixty percent of children with ADHD were treated with medications, and medications were the first intervention used in the study by McGuinness (2008).

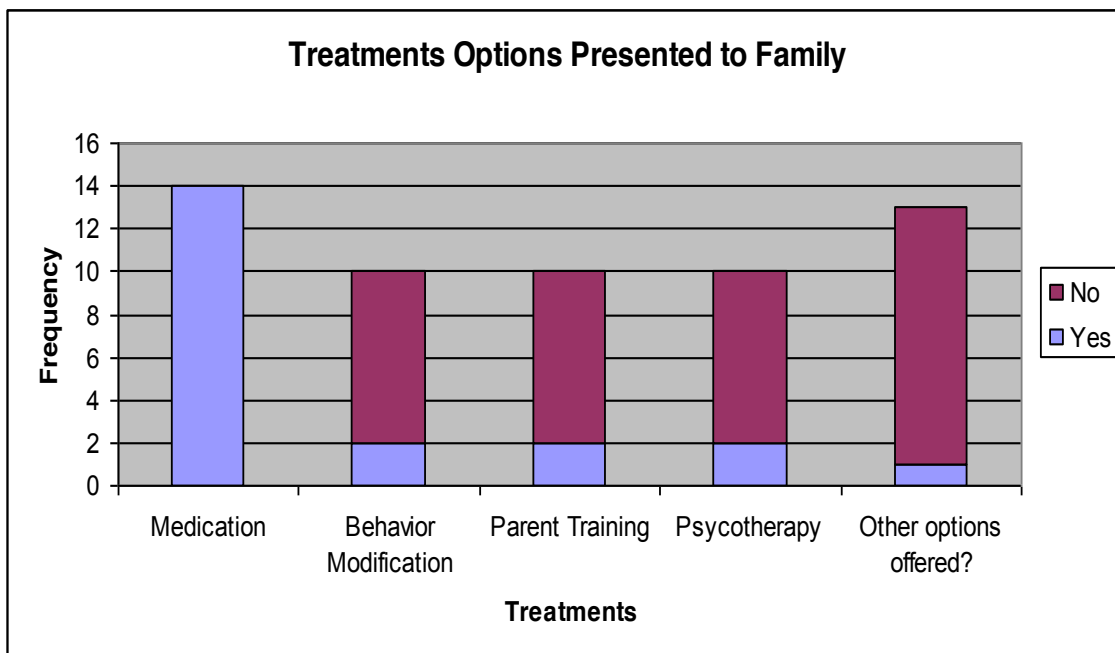


Figure 3. Treatment Options Presented to Family.

Data from this study showed that 71% of boys were diagnosed with ADHD, with a ratio of 2.5:1 boys/girls (see Table 2). This is similar with the results of the study by Klassen et al., (2004), in which they reported a ratio of 3:1 boys/girls ratio. Data also revealed that 35% of parents reported that they thought their children had ADHD by between the ages of 6 to 10 years, and 50% of the parents reported their child was actually diagnosed between the ages of 6 and 10 years of age. This is consistent with the study findings by DeNisco et al. (2005), in which the average age of diagnosis was between 8 and 9 years.

Table 2.

Child's Demographics

	Frequency	Percentage
Gender		
Male	10	71.43
Female	4	28.57
Age you first thought child had ADHD		
0 – 2	1	7.14
3 – 5	6	42.86
6 – 10	5	35.71
11 - 14	2	14.29
Age child was diagnosed with ADHD		
3 – 5	5	35.71
6 – 10	7	50.00
11 – 14	2	14.29
Who diagnosed the child with ADHD		
Doctor (MD/DO)	7	50.00
Psychiatrist	6	42.86
Psychologist	1	7.14
Location of child's first ADHD assessment		
Family doctor's office	8	57.14
Psychiatrist's office	6	42.86
Type of school child attends		
Public	11	78.57
Private	3	21.43
Total hours in a day child watches TV/plays video games		
0 – 2	6	42.86
2 – 4	6	42.86
4 – 6	1	7.14
>6	1	7.14

In this study, 78% of the children were enrolled in a public school system. All children were involved with at least one extracurricular activity (see Figure 4). Twenty-nine of the children were involved in boy or girl scouts.

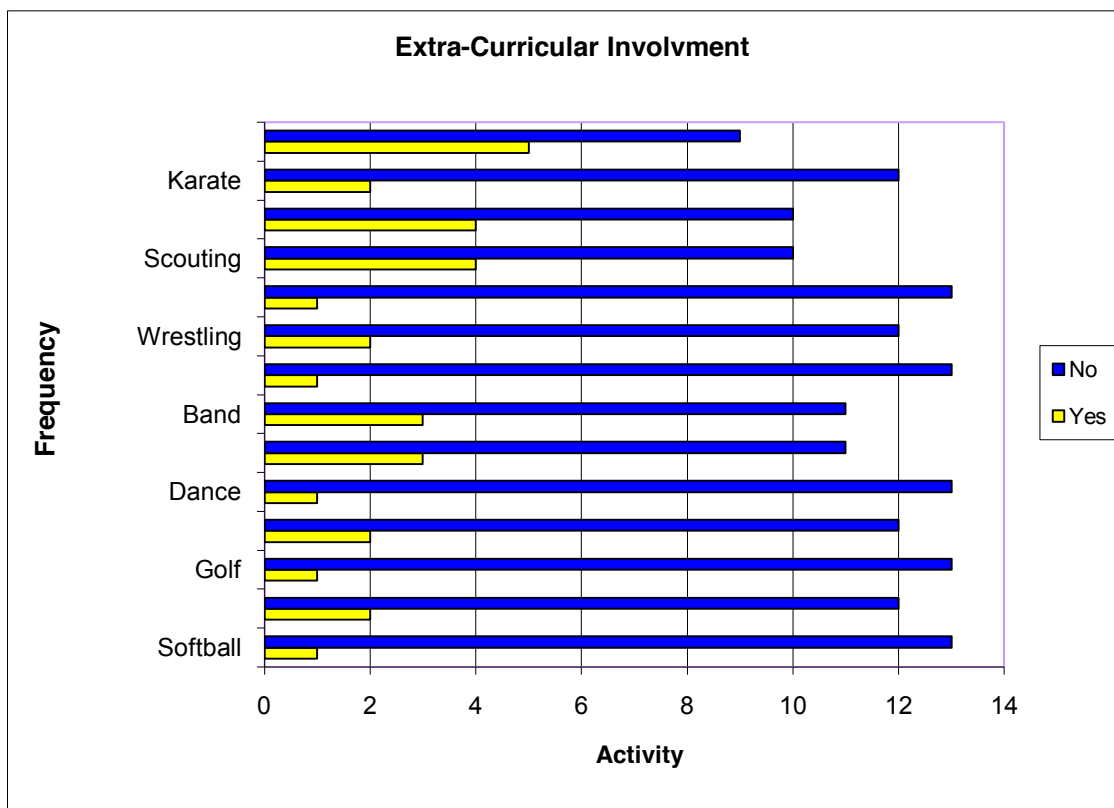


Figure 4. Extra-Curricular Involvement

Parents reported that 85% understood ADHD, but 85% desired more information on ADHD (see Figure 5). Sixty four percent of the parents were provided with educational websites or supportive information about ADHD.

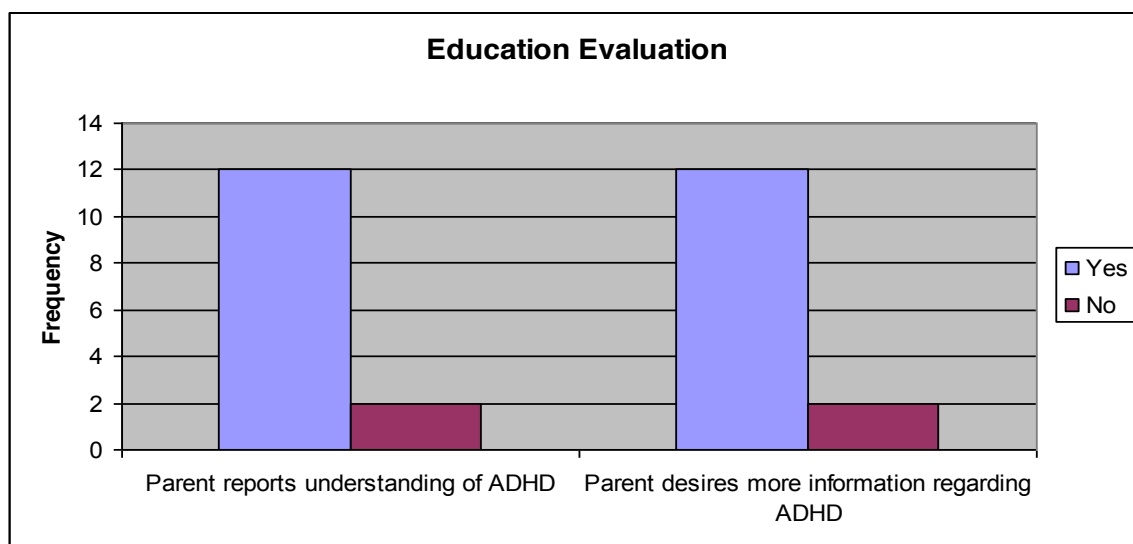


Figure 5. Education Evaluation.

This study showed 50% of the children had seen their HCP in the prior 3 months for a checkup on their ADHD. Twenty-eight percent of the parents reported they were unsure of when they should bring their child back to the HCP for management. Forty-nine percent of the parents in this study reported their child planned to see their HCP within the next 6 months. This finding is in agreement with the AAP guidelines recommending that clinicians schedule a follow up appointment.

The PPI had one open-ended question: What would you suggest to teach a new parent who has a child just diagnosed with ADHD? The following parents' responses emerged from this study and are categorized within the four concepts of McCubbin, Thompson, and McCubbin's Resiliency framework:

Interpersonal relationships:

- “Learn communication skills.”
- “How to speak to your child and get to rationalize vs. trying to get them to understand situations without yelling and arguing.”
- “Know your child and do not make drastic changes-understand side effects.”
- “Parent training: education on the disorder, medication and strategies to deal with behaviors, daily routines, discipline.”
- “It would be nice to know how to handle difficult situations with her”

Structure and function of the family:

- “Learn to communicate with your child who has ADHD, so the child can learn to rationalize and not throw tantrums.”
- “Parent training: education on the disorder, medications and strategies to deal with behaviors, daily routines, discipline.”
- Learning more about effective discipline techniques.
- Learn more about the medications and potential side effects.
- “Be patient with your child. Mornings and evenings may still be difficult as medicine will not be in child’s system.”
- “Use reputable websites for your research like Children and Adults with Attention Deficit Hyperactivity Disorder (CHADD).”
- “Learn as much as you can and get involved with the child.”

Development and well being:

- “Getting the child to understand the reasons why she can’t do something she wants to do without her throwing a temper tantrum and screaming and yelling at us. She doesn’t want to listen to the reasoning.”
- “Read, read, and read to understand how an ADHD mind works so rapidly, not only take an interest in behavior modification for the child, but modification of parent behavior is always needed to cope.”
- “Ask any question to help truly understand ADHD. Keep trying to understand if there’s other means such as diet, rest, activity that may help them, medication really helped but if there was another option, I would check or try.”

Community relationships:

- “Obtain as much information they can about it and to develop a plan with the school to keep the child’s needs attended to so the child can stay afloat.”
- “The doctor should listen more to what parent’s concerns are regarding medications and how they affect the child.”
- “If they don’t like the results from the medication, to try another medication until they find the right one. It’s wonderful when your child finds that light. Actually it’s life changing.”
- “Doctors should listen more to what parents say about medications.”
- “Staying current with research ideas or trends to offer without using medications.”
- “Wish the doctors would give us more information.”

- “Ask questions to help them (family) truly understand ADHD. Keep trying to understand if there’s other means, such as diet, rest, activity that may help the child. Yes, medication really helped but, if there was another option I would check or try.”
- “Trust your instincts, listen to your doctor. Research various websites to get as much info as you can. Be Patient with your child.”

The parents’ responses in this study revealed that parents wanted to learn more about ADHD. The parents’ identified a desire to learn how to cope with the diagnosis and help their child learn to communicate better, interact with others easier, learn discipline techniques, and learn what reputable websites and education is available. This study showed that parents were interested in other treatment options to help them cope and adjust with their child with ADHD.

Summary

This chapter addressed the description of the sample, demographic characteristics, and a discussion of the findings. The purpose of this study was to explore parent’s perceptions of the assessment and treatment options for their child diagnosed with ADHD. A total of 59 surveys were mailed out; 14 were returned for a 23% return rate. The qualitative responses helped the researcher understand parents’ perceptions of a desire to learn more about ADHD, medications, and interests in being informed of all treatment options available to make decisions for their child with ADHD.

Chapter V

Summary, Conclusions, Recommendations, and Implications

The purpose of this study was to explore parent's perceptions of the assessment and treatment options for their child diagnosed with Attention Deficit Hyperactivity Disorder. In this chapter, the summary, conclusions, recommendations for further research, and implications for practice are presented.

Summary

A descriptive survey design was utilized. Data were collected after IRB approval was obtained from both University of Wisconsin Oshkosh and a Midwest healthcare system. The sample comprised of 59 parents, who were 18 years of age and older, and whose children were diagnosed with ADHD or ADD. Three instruments were used for data collection: the Child Demographic Questionnaire, the Adult (parent) Demographic Questionnaire, and the Parents' Perception Instrument (PPI). Fourteen completed surveys were returned out of 59 that were mailed out, for a response rate of 23%. Data were analyzed using descriptive statistics.

Fifty-seven percent of parents sought a primary care setting for initial treatment of their child with behavioral symptoms. Ninety-two percent of parents perceived that treatment with medication was helpful. Eighty-five percent of children were managed in the primary care setting, even if they were diagnosed in a psychiatric setting. Eighty-five percent of the parents expressed a desire to learn more about ADHD.

Conclusions Based on Results of the Study

The findings showed that ADHD affects all social and economic strata of the population, and affects one and two parent families. Health care providers needs to be cognizant of the American Academy of Pediatrics diagnostic and evaluation guidelines and also the American Psychiatric Association DSM-IV-TR criteria when assessing children.

Attention deficit hyperactivity disorder can affect interpersonal relationships in the home, impacting how the child functions in the family and different types of settings; the development and well being of the child; and how the child and family interact with community, church, and the school system. The HCP may need to intervene and be a collaborator with the school and advocate on behalf of the child to obtain the attention and structure that is needed to help the child adjust in school. Understanding parents' perceptions of ADHD could assist HCPs in meeting the needs of the parents.

Incorporating McCubbin's Resiliency framework into the assessment, diagnosis and treatment options can impact how ADHD can be addressed, perceived, and understood by the family. The Resiliency model can be utilized by the HCP to identify treatment options that may help the child and family adapt and adjust to the ADHD diagnosis. Using a theoretical approach will guide the discussion of how ADHD affects the family function, interpersonal relationships, development and well being, and community relationships. The parent is identified as a key decision maker for their child in choosing treatment options.

The findings from the (MTACG, 1999) are still relevant and applicable to primary care, because the best outcome for the child would be for improved behavioral response

with the least side effects based on the treatment options that were provided. The current study found 85% of the children had their ADHD managed in primary care.

This study showed most of the assessments were done within the AAP guidelines, and medications were the most frequently offered treatment option. This study showed most patients had been controlled with their dose of medication and knew when to follow up with their healthcare provider. Despite being knowledgeable about ADHD, this study showed the parents would like to have more information about ADHD to help them cope with their child's behaviors and learn specific techniques to discipline or communicate more effectively with their child. Parents also identified they would be interested in alternative treatment options other than medication.

Implications for Practice

The findings emphasized 85% of the parents knew about ADHD, yet 85% of them would like to know more about ADHD. Implications for the HCP are to provide current educational materials, latest research findings, and explore available treatment options for the family. Offering parents and children websites, books, or support groups may provide more education to help the parents communicate more effectively and enhance the structure and function of the family. Working with the families and teaching proper socialization skills can help the child be more readily accepted by peers, improve ability to fit into community settings, and bolster the development and well being of the child.

Attention deficit hyperactivity disorder can require frequent visits to HCP to ensure effective dosing and monitoring for side effects of the medications. The AAP guidelines offer recommendations for a standardized way of assessing a child for ADHD.

However, following standards and recommendations does not mean this is not individualized care. By increasing awareness of these ADHD criteria and guidelines, and by understanding parents' perceptions, HCPs can provide evidence based treatment and care that is individualized to the family and child's needs. Healthcare providers must remember to tell the child and family when to return for a timely follow up to allow feedback from the family to ensure the child is meeting the best target outcomes.

With today's technological advancements, it is much easier to stay current with the AAP or DSM-IV-TR criteria, the AAP diagnosis and evaluation guidelines, and the AACAP treatment guidelines, by accessing different web sites such as the Agency for Healthcare Research and Quality (n.d.).

Healthcare providers must constantly screen for or diagnose ADHD at every opportunity they see the child in the office. The HCP must understand the long term consequences of ADHD on the child's ability to have interpersonal relationships with family, school personnel, and friends. Attention deficit hyperactivity disorder does impact the family structure, because the child with ADHD could be disruptive to the family relationships and take more energy and time from the parent and other children. In the school, the child might take more time from the teacher needing to keep the child on task.

Educating the child and family about medications and potential side effects of medications is important to provide the families with knowledge, so they can choose the right treatment that will work for them. Knowing what side effects to look for can help ensure the child will be monitored more closely to determine if medication regime is effective or if adjustments need to be made. Follow up is necessary in order to monitor

the child for changes in growth, vital signs, or any other side effects. The healthcare provider should recognize when the child's behaviors are not improving, discuss this with the family, and refer to psychiatry, if needed. The results of this study indicated that 85% of families have their child's ADHD managed by a primary care healthcare provider. The HCP needs to understand the DSM-IV-TR and the APA guidelines to assess the child according to standard guidelines, and to provide treatment options that are evidenced-based. This study showed that 85% were managed in a primary care setting, in that HCPs may encounter the chief complaint of ADHD often, and need to be efficient at assessing and providing treatment options.

Implications for Education

The literature review identified that misinterpretation of the different guidelines can occur among HCPs, and education of healthcare providers can help standardize the assessment process. There is opportunity to identify educational needs of the HCP, so that they can stay current on treatment options, become involved in changing policy, and educate other HCPs to become aware of the guidelines. There are implications for the HCPs to practice taking more time to educate the patient and child about ADHD and educate the family about the assessment process and all treatment options so the family.

Implications for Administration

With increasing prevalence of ADHD, an increase in office visits to primary care could occur and may indicate a need for more HCPs to manage rising patient care case loads. There would be a financial commitment needed from administration for a plan on

how to handle increased patient appointments. The HCP can be involved on committees and gain administrative support for these efforts.

Recommendations for Further Research

Ongoing research is needed to find how HCPs utilize the AAP guidelines and DSM-IV-TR criteria for ADHD. More research needs to be done to demonstrate value in how the HCP treats and manages ADHD in the primary care setting. Ongoing research is recommended to assess how providers utilize the guidelines and offer alternative treatment options.

Another potential research opportunity would be to explore if there is an association of increased number of ADHD diagnosis based on the number of activities a child is involved with or an association with the number of hours spent watching television.

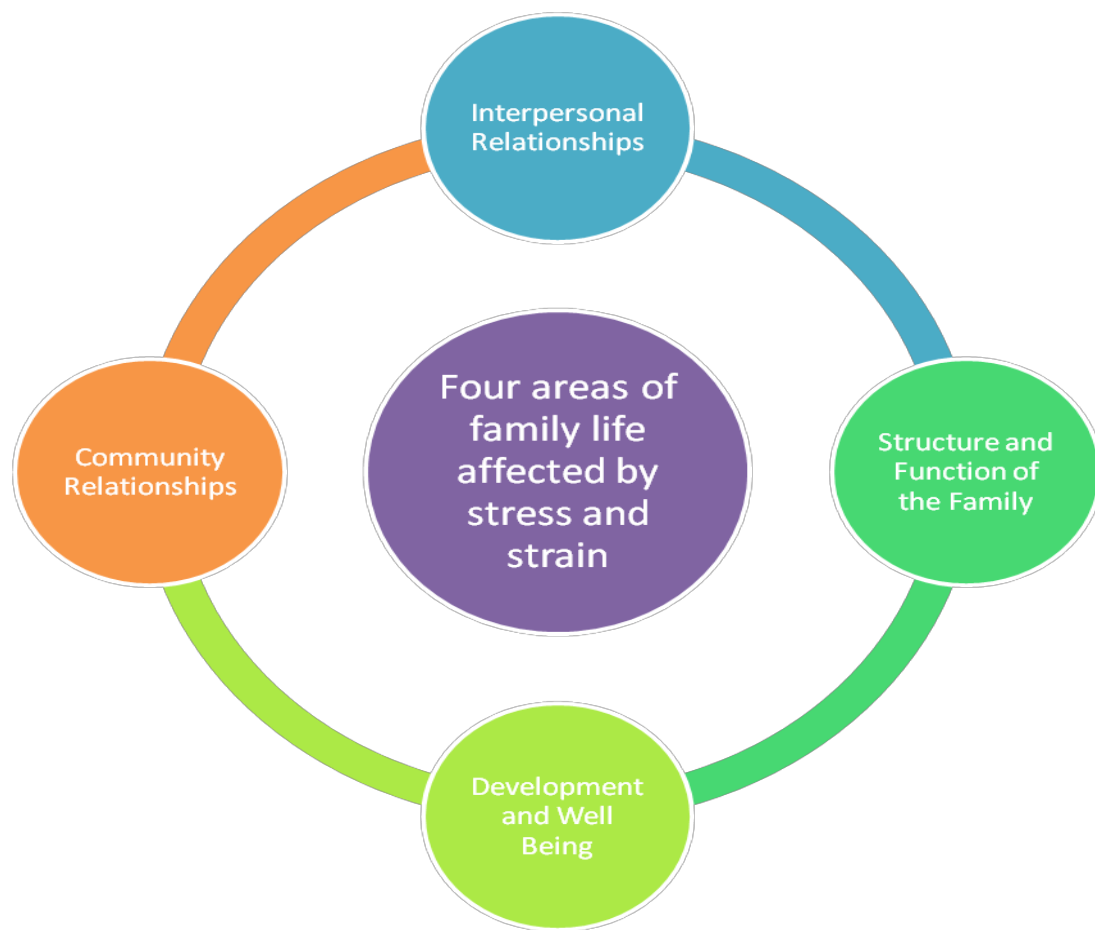
Qualitative studies could be done on ADHD, such as asking about the lived experience of having a child with ADHD. Another option would be to do a qualitative study about the health related quality of life for a child with ADHD. A quantitative study could be done that surveys the parents' understanding of ADHD.

Summary

This chapter presented a summary of the results, conclusion, limitations, and implications for practice, education, administration, and recommendations for further research. Understanding parents' perceptions of assessment and treatment options for ADHD can help the HCP with treatment options for the child diagnosed with ADHD. Referencing the Resiliency model could offer treatment options that empower the child

with ADHD learn skills to increase the quality of personal relationships, the child's self esteem and well being, and help the child function in the family and other community relationships. Utilizing evidenced based guidelines, and understanding parents' perceptions, along with clinical expertise, can assist the HCP to manage the child with ADHD in primary care.

APPENDIX A
RESILIENCY MODEL



Resiliency Model

For ADHD

APPENDIX B
CHILD DEMOGRAPHIC QUESTIONNAIRE

Child Demographic page. Fill in the blank or Circle the response. Your answers are confidential. You will not be identified. Do not put your name on this.

1. What is your child's gender?

Male ___ Female ___

2. At what age did you first think your child had ADHD?

0-3 ___

3-5 ___

6-10 ___

11-14 ___

>15 ___

3. At what age was your child officially diagnosed with ADHD?

0-3 ___

3-5 ___

6-10 ___

11-14 ___

>15 ___

4. Who diagnosed your child with ADHD?

Nurse Practitioner ___

Doctor (MD/DO) ___

Therapist/Counselor ___

Psychiatrist ___

Psychologist ___

Other (Please describe) _____

5. Location of where you brought your child first for an assessment for ADHD?

Family doctor office _____

Psychiatry office _____

6. What type of school does your child attend?

Public ___

Private ___

Home ___

7. Circle any of the following activities that your child with ADHD is involved in throughout the school year/summer.

Softball	Soccer	Golf	Basketball	Dance
Baseball	Band	Chorus	Wrestling	Volunteer work

Scouting _____ Football _____ Karate _____

Other _____

8. How many total hours a day does your child watch TV and/or play video games?

0-2 ___ 2-4 ___ 4-6 ___ >6 ___

APPENDIX C
ADULT DEMOGRAPHIC QUESTIONNAIRE

DEMOGRAPHIC DATA FOR ADULT FAMILY MEMBER

The following questions pertain to the person filling out this form. Please place a checkmark next to the area that applies.

1. Gender

Male _____ Female _____

2. Your relationship to the child

Parent _____ Guardian _____ Step-Parent _____ Other (Please Describe)

3. Current marital status

Single _____

Married _____

Living with another _____

Divorced _____

Separated _____

Widowed _____

4. Number of adults in home

1 _____ 2 _____ 3 _____ >3 (Please enter #) _____

5. Age of adults in the home

18-25 _____

26-30 _____

31-35 _____

36-40 _____

41-45 _____

46-50 _____

51-55 _____

56-60 _____

>60 _____

6. What is the highest level of education you have completed? (The person filling out the form)

Elementary _____

High school/Equivalent _____

Vocational/Technical School _____

Bachelor's Degree _____

Master's Degree _____

Doctoral Degree _____

Professional (MD, DO) _____

7. How would you classify yourself?

Caucasian/White _____
 Arab _____
 Latino _____
 Hispanic _____
 Black _____
 Native American _____
 Asian/Pacific Islander _____
 Multi-Racial _____
 Other _____

8. Family income

\$0-----\$19,999 _____
 \$20,000-\$34,999 _____
 \$35,000-\$49,999 _____
 \$50,000-\$64,999 _____
 \$65,000-79,999 _____
 > \$80,000 _____

9. Employment status

Employed full time _____
 Employed part time _____
 Unemployed _____
 Disability _____
 Retired _____

10. Which of the following best describes the area you live in?

Urban _____ Suburban _____ Rural _____

11. Number of children in family

1 _____ 2 _____ 3 _____ 4 _____ 5 _____ 6 _____ (Please enter # of kids if >6) _____

12. What Type of Insurance do you Have (check best answer)

Commercial _____
 Medicaid _____
 Medicare _____

APPENDIX D
PARENTS' PERCEPTION INSTRUMENT (PPI) FOR ADHD

Parents' Perception Instrument for ADHD

Circle or check all the answers that apply.

1. How long has your child been diagnosed with ADHD?

<1 year _____

1-2 years _____

3-4 years _____

>4 years _____

2. When you brought your child to the Doctor (MD) or Nurse Practitioner (FNP) to be evaluated for ADHD what did they do? Check any of the following that apply to your situation.

_____ It was an office visit with the doctor or nurse practitioner asking us questions and getting a history of my child's behaviors and symptoms at home, school or other situations.

_____ I filled out a questionnaire specifically about my child's behaviors.

_____ Labs were drawn

_____ Our family was referred to a psychiatrist or psychologist for further evaluation and or treatment.

3. Were you provided education or a website you could go to for additional support and information?

Yes

No

4. Circle all that apply: For treatment, was your child **offered**...

Medication Yes or No

Behavior modification Yes or No

Parent training Yes or No

Psychotherapy Yes or No

Was anything else offered Yes or No If yes, what?

5. Do you feel you understand ADHD _____ Yes or No?

6. Do you wish you could learn more about ADHD Yes or No?

Is your child taking medication? Yes or No

Is it helping? Yes or No

Has there been a dose change in the past 30 days? Yes or No

7. When was your last office visit with your doctor or nurse practitioner for your child to discuss the ADHD? Please circle.

< 1 month < 3 months < 6 months < 1 year > 1 year

8. When is your next appointment with your doctor or nurse practitioner to discuss ADHD? Please circle.

<1 month <3 months < 6 months < 1 year I do not know

9. Who currently manages your child's ADHD?

_____ Nurse Practitioner and/or Family doctor/Pediatrician

_____ Psychiatrist or Nurse Practitioner at a Psychiatric office

10. What would you suggest to teach a new parent who has a child just diagnosed with ADHD?

Thank you very much for participating and helping me to make a difference.

APPENDIX E
CHILD ASSENT FORM FOR AGES 10 – 12

Child's Assent Form (10 – 12 years old)

My name is Carla Wech. I am trying to learn more about Attention Deficit Hyperactivity Disorder (ADHD) because it is increasingly being diagnosed in children. My learning (study) involves asking your parents nine questions about when they found out you had ADHD, and how long you were diagnosed etc. I have attached the questions and you can take a look at them.

If you say yes to your parents answering these questions on your behalf, you can sign the letter below and give it to your mom or dad. They will then sign it and mail it to the clinic address. I will not know who you are, only the clinic manager will know. You don't have to be afraid of anything going wrong with your treatment at the clinic. By saying yes to your parents to share information about your ADHD, you will help me and other nurses to know more about how to determine other children have ADHD and to provide better treatment options.

Other people will not know if you say yes. I will put things I learn about you together with things I learn about other children's ADHD, so no one can tell what things came from you. When I tell other people about my study, no one can tell who I am talking about.

Your parents have to say it's OK for you to give them permission to share about your ADHD. If you don't want your parents to share information about you, no one will be mad at you. If you want to share now and change your mind later, that's OK. You can stop at any time.

My telephone number is 920-434-9283. You can call me if you have questions about the study or about what I am learning, or if you decide you don't want your parents to share any information.

Agreement

I am giving permission to my parents to share information about my ADHD even though I know that I don't have to do it. Carla has answered all my questions.

I have been given a copy of this form.

Signature

Date

If you have any questions, please feel free to contact:
 Carla Wech, RN, BSN
 Family Nurse Practitioner Student
 UW Oshkosh, wehc63@uwosh.edu
 (920)639-3369

APPENDIX F
CHILD ASSENT FOR AGES 13 – UNDER 18

CHILD'S ASSENT FORM (13 – UNDER AGE 18)

I have read my parent's consent form and the researcher Carla Wech has explained the details of the study on that form. I understand that I am free to ask additional questions.

If I wish additional information regarding this research and my rights as a research subject, or if I believe I have been harmed by this study, I may contact the Protection of Human participants' office at UW Oshkosh.

I understand that participation in this study is voluntary and I may refuse to participate or may discontinue participation at any time without penalty, loss of benefits, or affect the quality of care I receive.

Agreement

Signature

Date

If you have any questions, please feel free to contact:

Carla Wech, RN, BSN
Family Nurse Practitioner Student
UW Oshkosh, wechc63@uwosh.edu
(920)639-3369

If you have any complaints about your participation in this study, or any questions about your rights as a participant, please call or write:

Chair, Institutional Review Board for Protection of Human Participants
Office of Grants & Faculty Development
Dempsey Hall, Suite 214
University of Wisconsin Oshkosh
Oshkosh, WI 54901
(920)424-3215

Although the chairperson may ask for your name, all complaints are kept in confidence.

APPENDIX G

UNIVERSITY OF WISCONSIN OSHKOSH IRB APPROVAL



November 15, 2010

Ms. Carla Wech
3493 Wilderness Trail
Green Bay, WI 54313

Dear Ms. Wech:

On behalf of the UW Oshkosh Institutional Review Board for Protection of Human Participants (IRB), I am pleased to inform you that your application has been approved for the following research: Parents' Perceptions of ADHD Assessment & Treatment Options.

Your research has been categorized as EXEMPT. This means you will not be required to obtain signed consent. However, unless your research involves only the collection or study of existing data, documents, or records, you must provide each participant with a summary of your research that contains all of the elements of an Informed Consent document, as described in the IRB application material. Permitting the participant, or parent/legal representative, to make a fully informed decision to participate in a research activity avoids potentially inequitable or coercive conditions of human participation and assures the voluntary nature of participant involvement.

Please note that it is the principal investigator's responsibility to promptly report to the IRB Committee any changes in the research project, whether these changes occur prior to undertaking, or during the research. In addition, if harm or discomfort to anyone becomes apparent during the research, the principal investigator must contact the IRB Committee Chairperson. Harm or discomfort includes, but is not limited to, adverse reactions to psychology experiments, biologics, radioisotopes, labeled drugs, or to medical or other devices used. Please contact me if you have any questions (PH# 920/424-7172 or e-mail:rauscher@uwosh.edu).

Sincerely,

Dr. Frances Rauscher
IRB Chair

cc: Dr. Jaya Jambunathan
1912

INSTITUTIONAL REVIEW BOARD
UNIVERSITY OF WISCONSIN OSHKOSH • 800 ALGOMA BLVD • OSHKOSH WI 54901
(920) 424-3215 • FAX (920) 424-3221
An Equal Opportunity/Affirmative Action Institution • <http://www.uwosh.edu/>

APPENDIX H
HEALTH CARE SYSTEM IRB APPROVAL

bellinhealth



January 4, 2011

Ms. Carla Wech, BSN, RN
3493 Wilderness Trail
Green Bay, WI 54313

Dear Ms. Wech:

The Bellin Health Corporate Institutional Review Board (CIRB) had two members review your proposed study titled, "Parent's Perception of Child's ADHD Assessment and Treatment Options." You have made the recommended changes that were suggested by the reviewers and with these changes, the IRB members have found the study eligible for an expedited review. These findings constitute an approval for you to proceed from the IRB perspective.

Changes to any of the materials you presented *must* be sent to Bellin's IRB.

The reviewers noted the precautions that you are taking to protect the identity of the participants in the study. Any breach of confidentiality or any other unexpected adverse event related to the study will need to be reported to the IRB in a timely matter.

Please notify the IRB upon completion of this study.

Thank you for the opportunity to review your study. Please feel free to contact Amy Thompson, CIRB Coordinator, if you have any questions at 433-7856 or asthom@bellin.org

Sincerely,

William Wanamaker, MD
CIRB Chairperson

APPENDIX I
CLINIC SITE APPROVAL LETTER

bellinhealth
FAMILY MEDICAL CENTER
Howard

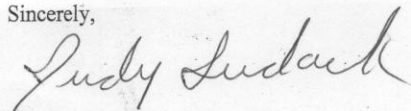


October 29, 2010

To Whom It May Concern:

Bellin Health Howard is willing to do a report on our patients via diagnosis code for ADHD and ADD for our Nurse Practitioner student, Carla Wech Rn.

Sincerely,



Judy Ludack
Medical Center Manager

APPENDIX J

INTRODUCTORY LETTER TO PARTICIPANTS AND INFORMED CONSENT

Participant Letter and Informed Consent

My name is Carla Wech, RN, BSN, and I am a Graduate Nursing student completing my Masters Degree as a Family Nurse Practitioner at the University of Oshkosh, Wisconsin. I am interested in learning about Attention Deficit and Hyperactive Disorder (ADHD) since there are an increasing number of children being diagnosed with ADHD.

As a future Nurse Practitioner, I would appreciate your participation in this study as it will assist me in understanding how families perceive the assessment and treatment options that are provided to them. The findings from this study will help me as well as other primary care Health Care Provider HCP in learning how to care for children with ADHD by understanding parent's perception. I was given approval from UW-Oshkosh and Bellin Health to conduct this survey.

Your responses will be completely anonymous and confidential. We do not want your name or address on the responses. Participation is completely voluntary and optional. You were randomly selected to participate in the study by the diagnosis code on your child's chart of having ADD or ADHD. I was not able to see the names of the people who were being sent the questionnaire. An office worker labeled the envelopes for me. As part of this study, you will complete two short demographic forms in addition to completing a questionnaire about your perception about the assessment and treatment options you were provided about your child's diagnosis of ADHD. Returning the completed packet in the mail with postage paid for by the researcher implies consent. There are no risks identified if you participate.

The questionnaires will take approximately 20 minutes to complete. No information about you or your child will be released in any way that could identify you or your child. This study will be done anonymously. The medical clinics that do participate will receive the results of the survey by the summer 2011.

The results of this study may not benefit you directly. However, the study will enhance health care Health Care Provider HCP understanding of how parents perceive this process. This will help us all to provide similar assessments and treatment options for ADHD and also provide individualized care to each family and child to attain best outcomes. Thank you very much for your time and for considering to participate.

If you have any questions, please feel free to contact:

Carla Wech, RN, BSN
Family Nurse Practitioner Student
UW Oshkosh, wehc63@uwosh.edu
(920) 639-3369

If you have any complaints about your participation in this study, or any questions about your rights as a participant, please call or write:

Chair, Institutional Review Board for Protection of Human Participants
Office of Grants & Faculty Development
Dempsey Hall, Suite 214
University of Wisconsin Oshkosh
Oshkosh, WI 54901
(920) 424-3215

Although the chairperson may ask for your name, all complaints are kept in confidence.

APPENDIX K
AMERICAN PSYCHIATRIC DSM-IV-TR ADHD CRITERIA

DSM-IV-TR Criteria for Assessment of ADHD

I. Either A or B:

- A. Six or more of the following symptoms of inattention have been present for at least 6 months to a point that is inappropriate for developmental level:

Inattention

1. Often does not give close attention to details or makes careless mistakes in schoolwork, work, or other activities.
2. Often has trouble keeping attention on tasks or play activities.
3. Often does not seem to listen when spoken to directly.
4. Often does not follow through on instructions and fails to finish schoolwork, chores, or duties in the workplace (not due to oppositional behavior or failure to understand instructions).
5. Often have trouble organizing activities.
6. Often avoids, dislikes, or doesn't want to do things that take a lot of mental effort for a long period of time (such as schoolwork or homework).
7. Often loses things needed for tasks and activities (e.g. toys, school assignments, pencils, books, or tools).
8. Is often easily distracted.
9. Is often forgetful in daily activities.

Six or more of the following symptoms of hyperactivity-impulsivity have been present for at least 6 months to an extent that is disruptive and inappropriate for developmental level:

Hyperactivity

10. Often fidgets with hands or feet or squirms in seat when sitting still is expected.
11. Often gets up from seat when remaining in seat is expected.
12. Often excessively runs about or climbs when and where it is not appropriate (adolescents or adults may feel very restless).
13. Often has trouble playing or doing leisure activities quietly.
14. Is often "on the go" or often acts as if "driven by a motor".
15. Often talks excessively.

Impulsivity

16. Often blurts out answers before questions have been finished.

17. Often has trouble waiting one's turn.
18. Often interrupts or intrudes on others (e.g., butts into conversations or games).

II. Some symptoms that cause impairment were present before age 7 years.

III. Some impairment from the symptoms is present in two or more settings (e.g. at school/work and at home).

IV. There must be clear evidence of clinically significant impairment in social, school, or work functioning.

V. The symptoms do not happen only during the course of a Pervasive Developmental Disorder, Schizophrenia, or other Psychotic Disorder. The symptoms are not better accounted for by another mental disorder (e.g. Mood Disorder, Anxiety Disorder, Dissociative Disorder, or a Personality Disorder).

Based on these criteria, three types of ADHD are identified:

IA. ADHD, *Combined Type*: if both criteria IA and IB are met for the past 6 months

IB. ADHD, *Predominantly Inattentive Type*: if criterion IA is met but criterion IB is not met for the past six months

IC. ADHD, *Predominantly Hyperactive-Impulsive Type*: if Criterion IB is met but Criterion IA is not met for the past six months.

American Psychiatric Association. *Diagnostic and statistical manual of mental disorders*. (4th ed -TR.). (2000). Arlington, VA: American Psychiatric Association.

APPENDIX L
BEHAVIOR EXAMPLES OF A CHILD WITH ADHD

Inattention

Often has a very hard time paying attention, daydreams

- Often does not seem to listen
- Is easily distracted from work or play
- Often does not seem to care about details, makes careless mistakes
- Frequently does not follow through on instructions or finish tasks
- Is disorganized
- Frequently loses a lot of important things
- Often forgets things
- Frequently avoids doing things that require ongoing mental effort

Hyperactivity

- Is in constant motion, as if "driven by a motor"
- Cannot stay seated
- Frequently squirms and fidgets
- Talks too much
- Often runs, jumps, and climbs when this is not permitted
- Cannot play quietly

Impulsivity

- Frequently acts and speaks without thinking
- May run into the street without looking for traffic first
- Frequently has trouble taking turns
- Cannot wait for things
- Often calls out answers before the question is complete
- Frequently interrupts others

<http://www.healthychildren.org/english/health->

[issues/conditions/adhd/Pages/default.aspx](http://www.healthychildren.org/english/health-issues/conditions/adhd/Pages/default.aspx)

REFERENCES

- Agency for Healthcare Research and Quality. (2010). Retrieved from <http://guideline.gov/syntheses/synthesis.aspx?f=rss&id=25638>
- American Academy of Pediatrics. (2000). Clinical practice guideline: Diagnosis and evaluation of the child with attention deficit hyperactivity disorder. *Pediatrics*, *105*(5), 1158-1170.
- American Academy of Pediatrics. (2001). Clinical practice guideline: Treatment of the school-aged child with attention-deficit/hyperactivity disorder. *Pediatrics*, *108*(4), 1033-1044.
- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders*. (4th ed -TR.). Arlington, VA: American Psychiatric Association.
- Antonucci, D., Kunins, C., Manos, M., Lopez, F. A., & Kerney, D. L. (2010). Assessing effects of treatment with Lisdexamfetamine Dimesylate for pediatric ADHD using a parental survey. *CNS Spectrum*, *15*(4), 248-256.
- Arnsten, A. F. (2006). Fundamentals of attention deficit hyperactivity disorder: Circuits and pathways. *Journal of Clinical Psychiatry*, 7-12.
- Biederman, J., & Faraone, S. V. (2004). Attention deficit hyperactivity disorder a worldwide concern. *The Journal of Nervous and Mental Disease*, *192*(7), 453-454.
- Bussing, R., & Gary, F. A. (2001). Practice guidelines and parental ADHD treatment evaluations: Friends or foes. *Harvard Review of Psychiatry*, *9*(5), 223-233.
- DeNisco, S., Tiago, C., & Kravitz, D. (2005). Evaluation and treatment of pediatric ADHD. *Nurse Practitioner*, *30*(8), 14-23.

- Evans, S. W., Schultz, B. K., & Sadler, J. M. (2008). Psychosocial interventions used to treat children with ADHD. *Journal of Psychosocial Nursing, 46*(8), 49-57.
- Gau, S. S. (2007). Parental and family factors for attention deficit hyperactivity disorder in Taiwanese children. *Australian and New Zealand Journal of Psychiatry, 41*, 688-696.
- Ghanizadeh, A., & Zarei, N. (2010). Are GPs adequately equipped with the knowledge for educating and counseling of families with ADHD children. *BioMed Central, 11*(5), 1-5.
- Klassen, A. F., Miller, A., & Fine, S. (2004). Health-related quality of life in children and adolescents who have a diagnosis of attention-deficit hyperactivity disorder. *Pediatrics, 114*(5), e541-e547.
- Lopez-Munoz, F., Alamo, C., Quintero-Gutierrez, F. J., & Garcia-Garcia, P. (2008). A bibliometric study of international scientific productivity in attention-deficit hyperactivity disorder covering the period 1980-2005. *European Child and Adolescent Psychiatry, 17*, 381-391.
- Magill, E. V. (2009). Alternative treatment methods for ADHD: Implications for FNP's. *The American Journal for Nurse Practitioners, 9*-21.
- McCarthy, S., Cranswick, N., Potts, L., Taylor, E., & Wong, I. C. (2009). Mortality associated with Attention Deficit Hyperactivity Disorder (ADHD) Drug Treatment. *Drug Safety Journal, 32*(11), 1089-1096. doi: 0114-5916/09/0011-1089
- McCleary, L. (2002). Parenting adolescents with attention deficit hyperactivity disorder: Analysis of the literature for social work practice. *Health & Social Work, 27*(4), 285-292.

- McCubbin, H. I., Thompson, A. I., & McCubbin, M. A. (1996). *Family assessment Resiliency, coping and adaptation*. Madison, WI: University of Wisconsin Publishers.
- McGuinness, T. M. (2008). Helping parents decide on ADHD treatment for their children. *Journal of Psychosocial Nursing, 46*(8), 23-27.
- Mick, E., Biederman, J., Faraone, S. V., Sayer, J., & Kleinman, S. (2002). Case-control study of Attention-Deficit Hyperactivity Disorder and maternal smoking, alcohol use, and drug use during pregnancy. *Journal of the American Academy of Child & Adolescent Psychiatry, 41*(4), 378-385.
- Miller-Horn, J. W., Kaleyias, J., Valencia, I., Melvin, J. J., Khurana, D. S., Hardison, H. H., ... Kothare, S. V. (2008). Efficacy and tolerability of ADHD medications in a clinical practice. *Journal of Pediatric Neurology, 6*(6), 5-10.
- Morley, C. P. (2010). The effects of patient characteristics on ADHD diagnosis and treatment: A factorial study of family physicians. *Biomed Central Family Practice, 11*(11), 1-10. Retrieved from <http://www.biomedcentral.com/1471-2296/11/11>
- MTA Cooperative Group. (1999). A 14 month randomized clinical trial of treatment strategies for Attention Deficit Hyperactivity Disorder. *Archives of General Psychiatry, 56*, 1073-1086.
- Parent. In *Merriam Webster's online dictionary*. Retrieved from <http://www.merriam-webster.com/dictionary/parent>
- Polit, D. F., & Beck, C. (2008). *Nursing research: Generating and assessing evidence for nursing practice* (8th Ed.). Philadelphia: Lippincott, Williams & Wilkins.

- Pollak, Y., Shomaly, H. B., Weiss, P. L., Rizzo, A. A., & Gross-Tsur, V. (2010). Methylphenidate effect in children with ADHD can be measured by an ecologically valid continuous performance test embedded in virtual reality. *CNS Spectrums, 15*(2), 125-130.
- Riley, A. W., Lyman, L. M., Spiel, G., Dopfner, M., Lorenzo, M. J., & Ralston, S. J. (2006). The family strain index Reliability validity and factor structure of a brief questionnaire for families of children with ADHD. *European Child and Adolescent Psychiatry, 15*, 172-178.
- Saadah, M., & Saadah, L. (2004). Attention deficit hyperactivity disorder: Current status and future perspectives. *International Journal of Therapy and Rehabilitation, 11*(8), 381-388.
- Salmeron, P. A. (2009). Childhood and adolescent attention-deficit hyperactivity disorder: Diagnosis clinical practice guidelines and social implications. *Journal for the American Academy of Nurse Practitioners, 488-497*.
- Van der Oord, S., Prins, P.J., Oosterlaan, J., & Emmelkamp, P.M. (2007). Does brief clinically based intensive multimodal behavior therapy enhance the effects of methylphenidate in children with ADHD. *European Child and Adolescent Psychiatry, 16*(1).
- Vissers, S., Bitsko, R., Danielson, M., Perou, R., & Blumberg, S. (2010). Increasing prevalence of parent reported attention-deficit-hyperactivity disorder among children-United States, 2003-2007. *Morbidity and Mortality Weekly Report, 59*(44), 1439-1443. Retrieved from <http://web.ebscohost.com.www.remote.uwosh.edu/ehost/pdfviewer/pdfviewer?hid=110&sid=8241fc18-1cbd-4e6b-af1e-b812f4b02827%40sessionmgr115&vid=5>

- Waite, R., & Tran, M. (2009, August). Explanatory models and help seeking behavior for Attention Deficit Hyperactivity Disorder among a cohort of postsecondary students. *Archives of Psychiatric Nursing, 24*(4), 247-259. doi: 10.1016/j.apnu.2009.08.004
- Wilens, T., Haahes, A., Biederman, J., Bredin, E., Tanguay, S., Kwon, A., & Faraone, S. (2005). Influence of parental SUD and ADHD in their offspring: Preliminary results from a pilot controlled family study. *American Journal on Addictions, 14*(2), 179-187.