Teens’ Perceptions About Attention Deficit Disorder/Attention Deficit Hyperactivity Disorder Medications and Adaptation to Attention Deficit Disorder/Attention Deficit Hyperactivity Disorder

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2006
STATEMENT BY AUTHOR

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The purpose of this study was to describe teens’ perceptions about Attention Deficit Disorder/Attention Deficit Hyperactivity Disorder (AD/HD) medications and adaptation to AD/HD including decision-making about taking prescribed AD/HD medications. Results of this investigation will inform school nursing practice and may enhance positive health outcomes for teens with AD/HD. A convenience sample of 15 teens aged 14-17 with parent reported AD/HD were interviewed using semi-structured interviews organized into Roy’s four modes of adaptation. Transcriptions of audio taped interviews were analyzed inductively for sub themes within each mode of adaptation: Physiologic-Neurological sub theme was “medications are a hassle but they work; Role function (student) sub theme was “I do better in school when I take the meds”; interdependence (family & friends) sub theme was “With meds things are better with my family and friends don’t know I am any different”; and self-concept/group identity sub theme was “I’m just an everyday teenager, pretty much”. The main theme was “Meds help me.”
CHAPTER ONE

Introduction

The purpose of this study was to describe teens’ perceptions about Attention Deficit Disorder/Attention Deficit Hyperactivity Disorder (AD/HD) medications and adaptation to AD/HD including decision-making about taking prescribed AD/HD medications. Results of this investigation will inform school nursing practice and may enhance positive health outcomes for teens with AD/HD.

Background

Attention Deficit Disorder (ADD) refers to persistent patterns of inattention and/or hypoactive-impulsivity that is more frequently displayed and more severe than is typically observed in individuals at a comparable level of development (DSM IV, 2000) beginning in early childhood and may continue into adulthood. If symptoms include a fifth symptom, hyperactivity, the diagnosis is Attention Deficit Hyperactivity Disorder (AD/HD) (NIMH, 2000; Houck, King, Tomlinson, Vrabel, and Wecks, 2002; Chadd, 2001). The diagnosis has changed from ADD +/- hyperactivity to the widely accepted Attention-Deficit/Hyperactivity Disorder AD/HD. AD/HD affects between 3% and 7% of school-age children in the United States. Almost 4 million youth ages 3 to 17 (6%) have been diagnosed with AD/HD and boys are more than twice as likely as girls to have an AD/HD diagnosis (CDC, 2004). This disorder is highly familial, linked to genetic factors and individuals with chronic attention impairments have probably existed in every generation but seen simply as underachieving, lazy, immature, or unmotivated (Brown, 2000). Emotionally charged beliefs range from the extreme view of AD/HD as a myth or
fiction (Clark, 2002) to the opposite view of many dedicated researchers documenting physical, mental, behavioral, and social data exhibiting AD/HD as a disability or mental diagnosis (CHADD, 2002). The debate and defense of the authenticity of AD/HD further victimizes children and families who need help in dealing with the physical, mental, behavioral, and social aspects of this condition. The Penrice chronology in Table 1 gives an abbreviated overview of the recognized history of AD/HD.
TABLE 1: AD/HD Timeline

<table>
<thead>
<tr>
<th>Date</th>
<th>Historical Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>1848</td>
<td>German physician Heinrich Hoffmann, M.D. writes a children’s poem, “Fidgety Philip,” that describes hyperactive behavior</td>
</tr>
<tr>
<td>1902</td>
<td>British pediatrician Sir George Frederick Still, M.D. describes hyperactivity in children as a “defect of moral control.”</td>
</tr>
<tr>
<td>1930s</td>
<td>“Post-Encephalitic Disorder” is coined after encephalitis epidemic of 1917-18, and resulting brain damage is thought to be the cause of hyperactivity. “Minimal Brain Damage” is also used to describe the disorder.</td>
</tr>
<tr>
<td>1937</td>
<td>Doctors reported that stimulant medication helped control hyperactive symptoms.</td>
</tr>
<tr>
<td>1960s</td>
<td>“Minimal Brain Dysfunction” becomes the prevalent term for the disorder in Mid-1960s Stimulant medication becomes common treatment for AD/HD.</td>
</tr>
<tr>
<td>1968</td>
<td>The American Psychiatric Association (APA) establishes a diagnostic category, Diagnostic and Statistical Manual of Mental Disorders (DSM–II), for “Hyperkinetic Reaction of Childhood.”</td>
</tr>
<tr>
<td>1970s</td>
<td>Impaired attention and impulse control, in addition to hyperactivity, are recognized as primary symptoms.</td>
</tr>
<tr>
<td>1980</td>
<td>The APA DSM-III officially refers to the disorder for the first time as Attention Deficit Disorder (ADD) +/- Hyperactivity. Over the next 20 years, the APA further defines the disorder, ultimately arriving at today’s widely accepted Attention-Deficit/Hyperactivity Disorder (AD/HD). The latest version of the diagnostic manual is the DSM-IV-TR published in 2000.</td>
</tr>
<tr>
<td>1998</td>
<td>National Institutes of Health Consensus Statement on AD/HD.</td>
</tr>
<tr>
<td>1999</td>
<td>National Institute of Mental Health Multimodal Treatment Study of Children with AD/HD (MTA) results published.</td>
</tr>
</tbody>
</table>

*(J. Penrice as cited in Eli Lilly, 2004)*
Symptoms arise in early childhood, unless associated with some type of brain injury later in life. The diagnosis of mild, moderate, or severe AD/HD often causes distress and grief to the children and their families (NIMH, 2000). The official diagnostic criteria state that the onset of symptoms must occur before age seven. Barkley (1998) argued that diagnostic criterion should be broadened to include onset of symptoms anytime during childhood. From 40-50% of children diagnosed with AD/HD have fewer problems or their AD/HD behaviors disappear as they go through puberty (Silver, 2004). The disorder is more frequent in males than in females, with male: female ratios ranging from 2:1 to 9:1, depending on the type (i.e., the Predominantly Inattentive Type may have a gender ratio that is less pronounced) and setting (i.e., clinic-referred children are more likely to be male).

Guidelines for determining whether a person has AD/HD are very specific due to the fact that everyone exhibits these behaviors at one time or another. Six of the nine criteria must be exhibited before the age of seven in either or both of the DSM-IV categories. Symptoms must be present for at least six months; symptoms present in two or more settings, and are more frequent or severe than children of the same age group.
TABLE 2: Criteria for Three Primary Subtypes of Attention Disorders

<table>
<thead>
<tr>
<th>AD/HD Predominately Inattentive type: AD/HD-I</th>
<th>AD/HD Predominately Impulsive type: AD/HD-HI</th>
<th>AD/HD Combined Impulsive type: AD/HD-C</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fails to give close attention to details or makes careless mistakes. Has difficulty sustaining attention. Does not appear to listen. Struggles to follow through on instructions. Has difficulty with organization. Avoids or dislikes tasks requiring sustained mental effort. Loses things. Is easily distracted. Is forgetful in daily activities. <strong>DSM 314.00</strong></td>
<td>Fidgets with hands on feet or squirms in chair. Has difficulty remaining seated. Runs about or climbs excessively. Difficulty engaging in activities quietly. Acts as if driven by a motor. Talks excessively. Blurs out answers before questions have been completed. Difficulty waiting or taking turns. Interrupts or intrudes upon others. <strong>DSM 314.01</strong></td>
<td>Individual meets six or more symptoms on inattention and six or more symptoms of hyperactivity-impulsivity and symptoms persist for at least six months. <strong>DSM 314.01</strong></td>
</tr>
</tbody>
</table>

Treatment typically includes use of medications to help control symptoms, sometimes in conjunction with counseling and supportive services in schools and communities (Solanto, Arnsten, & Castellanos, 2001). Some people get better results from one medication, some from another. It is important for the family and the prescribing healthcare provider to find the right medication and the right dosage (Anastopoulos & Shelton, 2001). The two major medication types are Central Nervous System (CNS) psychostimulants and non-stimulants (CHADD, 2003). For decades, medications have been used to treat the symptoms of AD/HD. The controlled class of drugs known as stimulant medications seem to be the most effective (Farley, 1997; Johnson et al, 2005).

Despite progress in the assessment, diagnosis, and treatment of AD/HD, this disorder and its treatment have remained controversial, especially in the use of psychostimulants for both short and long-term treatment (NIHCS, 1998).
TABLE 3: List of Psychostimulants Used for Treatment of AD/HD

<table>
<thead>
<tr>
<th>Trade Name</th>
<th>Generic Name</th>
<th>Approved Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adderall</td>
<td>amphetamine</td>
<td>3 and older</td>
</tr>
<tr>
<td>Adderall XR</td>
<td>amphetamine extended release</td>
<td>6 and older</td>
</tr>
<tr>
<td>Concerta</td>
<td>methylphenidate (long acting)</td>
<td>6 and older</td>
</tr>
<tr>
<td>Cyclert*</td>
<td>pemoline</td>
<td>6 and older</td>
</tr>
<tr>
<td>Dexedrine</td>
<td>dextroamphetamine</td>
<td>3 and older</td>
</tr>
<tr>
<td>Dextrostat</td>
<td>dextroamphetamine</td>
<td>3 and older</td>
</tr>
<tr>
<td>Focalin</td>
<td>dexamethylphenidate</td>
<td>6 and older</td>
</tr>
<tr>
<td>Metadate ER</td>
<td>methylphenidate (extended release)</td>
<td>6 and older</td>
</tr>
<tr>
<td>Metadate CD</td>
<td>methylphenidate (extended release)</td>
<td>6 and older</td>
</tr>
<tr>
<td>Ritalin</td>
<td>methylphenidate</td>
<td>6 and older</td>
</tr>
<tr>
<td>Ritalin SR</td>
<td>methylphenidate (extended release)</td>
<td>6 and older</td>
</tr>
<tr>
<td>Ritalin LA</td>
<td>methylphenidate (long acting)</td>
<td>6 and older</td>
</tr>
</tbody>
</table>

*Because of its potential for serious side effects affecting the liver, Cylert should not ordinarily be considered as first-line drug therapy for AD/HD.
* "Approved age" means that the drug has been tested and found safe and effective in children of that age (NIMH, 2003) (NIHCS, 1998).

These stimulants are Schedule II medications which means they are deemed by the Drug Enforcement Agency (DEA) to be controlled substances. Schedule II drugs have a high potential for abuse and extreme liability for physical and psychological dependence. Charach, Ickowicz, and Schachar (2004) found that psychostimulants improve AD/HD symptoms for up to 5 years, but adverse effects persist. Loss of appetite was found to be the most common adverse effect. These stimulant drugs have many possible side effects including psychic stimulation, euphoria, talkativeness, increased heart conduction, high blood pressure, insomnia, decreased appetite, weight loss, dysphoria (definition from Tabers, 1989: exaggerated feeling of depression and unrest without apparent cause, a mood of general dissatisfaction, unpleasantness, restlessness, anxiety, discomfort, unhappiness), possible reduction in growth velocity with chronic use, rebound phenomena of depression as the medicine wears off, development of tics,
and paranoid hallucinations and delusions (Brown, 2000; Hopfer & Vallerand, 1998). Federal Drug Administration is evaluating Canada's suspension of sale of Adderall XR products due to sudden unexplained death in children taking Adderall and Adderall XR (FDA, 2005).

The non-stimulant medication, Strattera (generic: atomoxetine), was approved by the FDA as the only non-stimulant medication for children, adolescents, and adults November 26, 2002. Strattera is a selective nor epinephrine reuptake inhibitor taken in once or twice daily oral capsules manufactured by Eli Lilly (Lilly, 2004). The medication, Strattera, works on the neurotransmitter nor epinephrine, whereas the psychostimulants primarily work on dopamine (NIMH, 2003; MedlinePlus, 2005). U.S. Food and Drug Administration Talk Paper (2004) warns of potential severe liver injury following reports of two patients (a teenager and an adult) who developed problems that had been treated with Strattera for several months, both of whom recovered. The new labeling will warn that medications should be discontinued in patients who develop jaundice or laboratory evidence of liver injury. Marketed since 2002 with millions of patients and with clinical trials of 6000 patients, Strattera previously had no indication of liver problems.

Accompanying Disorders

Increased attention is focused on the area of AD/HD and co-morbidity (Plitzka, Carlson & Swanson, 1999). The National Institutes of Mental Health (2003) issued a statement listing accompanying disorders as: learning disabilities, Tourette's disorder,
oppositional defiant disorder, conduct disorder, anxiety and depression, and bipolar disorder.

Attention problems can seriously interfere with school performance but are not learning disabilities in themselves (NIMH, 1993). Approximately 20-30 percent of children with AD/HD also have a specific learning disability (LD). Difficulty in understanding certain sounds or expressing oneself in words is the preschool challenge. In school age children, the LD may be in reading, spelling, writing, or arithmetic. Dyslexia, a reading LD, is quite widespread plaguing up to eight percent of the elementary age children with AD/HD (Jackson & Vessey, 1996).

A very small proportion of children with AD/HD have Tourette's Disorder, a neurological disorder, characterized by sudden, rapid, recurrent, non-rhythmic, stereotyped motor movement or vocalization such as eye blinks, facial twitches, or grimacing. Others may clear their throats frequently, snort, sniff, or bark out words. While only a small proportion of children with AD/HD have Tourette's, many of the cases of Tourette's disorder also have associated AD/HD. Both these conditions can be controlled with medication (NIMH, 2003; DSM IV TR, 2002).

One third to one half of all children with AD/HD, mostly boys, have another condition known as oppositional defiant disorder (ODD). These children are often defiant, stubborn, non-compliant, have outbursts of temper, or become belligerent. They argue with adults and refuse to obey (NIH Consensus Statement, 1998; Houck, et al, 2002).
About 20-40% of children with AD/HD may eventually develop conduct disorder (CD), with more serious antisocial behaviors. These children have a repetitive and persistent pattern of behavior in which the basic rights of others or major age-appropriate societal norms/rules are violated and may get into trouble at school or with the police. They may be aggressive and violate people and animals, destroy property, commit thefts, carry or use weapons, or engage in vandalism. These children or teens are at high risk for substance abuse (NIMH, 2003; DSM IV TR, 2002).

Some children with AD/HD often have accompanying anxiety or depression (Perwien, Hall, Swensen, & Swindle, 2004). Recognition and treatment will help them be better able to handle the problems that accompany AD/HD. Effective treatment of AD/HD can help alleviate the anxiety as the child is better able to master academic tasks (NIMH, 2003).

We do not have a diagnosis in the DSM IV of Bipolar disorder among children but symptoms of bipolar disorder are becoming more apparent in children with AD/HD. Symptoms such as a high level of energy, a reduced need for sleep, and mood cycling will probably be treated with a mood stabilizer such as lithium or Depakote. The provider will carefully consider whether the child should take one of the medications usually prescribed for AD/HD. If a stimulant medication is prescribed, it may be given in a lower dosage than usual (NIMH, 2003; Griffin, 2004).

Problem Statement

There are deficits in the literature regarding understanding of teens' own view about their experiences with these medications, how they decide whether or not to take
these medications, and what other strategies (other than medications) they may employ to manage their situations. Research about AD/HD has focused heavily on medication options and behavioral outcomes. The teens' own perspective is necessary for providing reliable information regarding effects of medications and treatments as experienced by the individual with AD/HD (Efron, Jarman, and Barker, 1998). Adherence to medical and behavioral therapy for children with AD/HD is difficult to attain even with greater improvement in symptoms (Charach, et al, 2004). Given these patient response patterns, the treatment may be suboptimal and may impact outcomes (Perwien, et al, 2004). The proposed study describing the teens' own perceptions of management of AD/HD may be the missing link for effective management of AD/HD with interventions in harmony with true adolescent thought and action.

Purpose Statement

The purpose of this study was to describe teens’ perceptions about Attention Deficit Disorder/Attention Deficit Hyperactivity Disorder (AD/HD) medications and adaptation to AD/HD including decision-making about taking prescribed AD/HD medications. Results of this investigation will inform school nursing practice with development of teen perceptions into taxonomy of themes and sub themes. This knowledge of teens’ perceptions about AD/HD will help determine how to best assist the teen in attaining positive adaptation for a better quality of life.

Roy Adaptation Model provided the conceptual framework for review of literature and research design. The research questions were:

1. What are perceptions regarding adaptation to AD/HD in the Physiological mode?
2. What are perceptions regarding adaptation to AD/HD in role function mode as a student?

3. What are perceptions regarding adaptation to AD/HD in the interdependence mode as experienced with family and friends?

4. What are perceptions regarding adaptation to AD/HD in the self-concept mode?

Significance of the Problem

Much of the literature calls AD/HD the most commonly diagnosed psychiatric disorder of childhood (Selekman, 2002; Brown, 2000; USDHHS, 1999) affecting conservatively 3-5 percent of all American children with some authorities citing the incidence could be much higher (Selekman & Snyder, 1996; Brown, 2000; Solanto, et al, 2001).

This disorder is costly to families and society. Families of children with AD/HD have increased levels of parental frustration, marital discord, and divorce. The direct financial costs of medical care for children/youth with AD/HD represent a serious burden for families as mental health problems are often not adequately covered with medical insurance. A precise estimate of the costs of this disorder to society is not available but these costs are large. National public school expenditures on behalf of students with AD/HD may have exceeded $3 billion in 1995. If this disorder has co morbid conduct, disorders the costs of violent crime and teenage pregnancy escalate. These individuals consume a disproportionate share of resources and attention from our health care system, criminal justice system, schools, and other social service agencies (NIHCS, 1998).
Significance to School Nursing

This disorder is perceived in a wide and diverse spectrum of controversy both in diagnostic criteria and in appropriate treatment. AD/HD is indeed an area of concern appropriately within the needs based assessment of the school nurse. School nurses recognize the necessity of partnering with teens and their families to provide comprehensive solutions that help teens maintain health and productivity (Houck, 2002; Frame, 2003). School nurse research will promote and support research based practice (Maughan, 2003). This study produced a new taxonomy of theme and sub themes of teens' perceptions regarding AD/HD useful for empowering school nurses with knowledge. School nurses will have informed strategies to develop interventions to guide families and teens with AD/HD, healthcare providers, schoolteachers and staff, and communities in a multidisciplinary effort toward regulating stimuli for an adaptive educational experience compatible for teens.

The role of school nursing for teens is to promote adaptation toward holistic functioning with an emphasis on coping mechanisms (in areas of neurological, role function, interdependence, and self-concept/group identity). This frees energy for positive adaptive health responses and decrease ineffective health responses. An adaptive health response is one that increases energy for life. Energy is linked to health (Roy, n.d.).

Summary

The purpose of this study is to describe perceptions regarding adaptation to their AD/HD, including decision-making about taking prescribed AD/HD medications. Attention Deficit Disorder (ADD) refers to persistent patterns of inattention and/or hypoactive-
impulsivity that is more frequently displayed and more severe than is typically observed in individuals at a comparable level of development (DSM IV, 2000) that begin in early childhood and can continue into adulthood. AD/HD affects between 3% and 7% of school-age children. Almost 4 million youth ages 3 to 17 (6%) have been diagnosed with AD/HD, with boys twice as likely as girls to have an AD/HD diagnosis (CDC, 2004). The area of AD/HD co-morbidity is exploding. Teens with AD/HD often have co-morbidities such as learning disabilities, Tourette’s Syndrome, oppositional defiant disorder, conduct disorder, anxiety and depression, and bipolar disorder (NIMH, 2003).

Treatment for AD/HD typically includes use of medications to help control symptoms, sometimes in conjunction with counseling and supportive services in schools and communities. The two major medication types are Central Nervous System (CNS) psychostimulants and non-stimulants. Despite progress in the assessment, diagnosis, and treatment of AD/HD, this disorder and its treatment have remained controversial, especially in the use of psychostimulants for both short-and long-term treatment (NIHCS, 1998).

Research about AD/HD has focused heavily on medication options and behavioral outcomes. There are deficits in the literature regarding understanding of own view about their experiences with these medications, how they decide whether or not to take these medications, and what other strategies (other than medications) they may employ to manage their situations. The teen’s perspective is necessary for providing reliable information regarding effects of medications and treatments as experienced by the individual with AD/HD (Efron, et al, 1998).
This disorder is perceived in a wide and diverse spectrum of controversy and is indeed an area of concern appropriately within the needs based assessment of a school nurse. School nurses recognize the necessity of partnering with teens and their families to provide comprehensive solutions that help teens maintain health and productivity (Houck, 2002). This study provides knowledge of teens’ perceptions about AD/HD for school nurses to develop informed strategies to assist the teen in attaining adaptation for a better quality of life.
CHAPTER TWO

Conceptual Framework/Literature Review

The purpose of this study was to describe perceptions about AD/HD medications and adaptation to AD/HD including decision-making about taking prescribed AD/HD medications. The following literature review of AD/HD was organized by means of Roy’s four effector behavioral modes: 1) Physiologic-physical, 2) Role function, 3) Interdependence, and 4) Self-concept/group identity. This chapter is an overview of Roy’s Adaptation Model (RAM), an overview of adolescence as a developmental stage, and presents literature relevant to teens with AD/HD categorized within RAM.

The exposure to excessive demands or environmental conditions that cause emotional upset and tension to teens with AD/HD must be met with coping mechanisms within areas of physiology, role function, interdependence, and perceptions of self (Roy, 1993). The paucity of literature specifically addressing the perceptions of teens accents the need for this study. The literature on this specific point of interest is organized within the worldview of Callista Roy’s Adaptation Model (RAM) in the four modes/modes.

Overview of Roy and Adolescent Development

RAM’s holistic worldview integrates the inner and outer processes of the person interacting within and without the person to move toward either adaptation or ineffectiveness of the person and the environment in which the person functions. RAM assumes humans are individuals and groups: 1) sharing in creative power, 2) behaving purposefully, 3) possessing holism, and 4) striving to maintain integrity and to realize the need for relationships. Roy’s concepts of humanism and veritivity are described as based
on the stability, teleology, unity, and universality of truth (Roy, n.d.). Persons have mutual relationships with the world and God. The nurse/patient relationship is privileged to promote effective adaptation by applying nursing interventions/actions (Hanna & Roy, 2001).

The key concepts of RAM are the four-effector behavioral modes defined as:

Physiologic-physical: Five needs-oxygenation; nutrition, elimination, activity and rest;
Protection: four complex processes-senses; fluid, electrolyte, and acid-base balance; neurological function; endocrine function. Role function: Need is psychic and spiritual integrity so that one can be or exist with a sense of unity, meaning, and purposefulness in the universe. Interdependence: Need is to achieve relational integrity using process of affectional adequacy, i.e., the giving and receiving of love, respect, and value through effective relations and communication. Self-concept/group identity: the composite of beliefs and feelings that one holds about oneself at a given time, formed from internal perceptions and perceptions of other’s reactions, and directing one’s behavior (Roy, n.d.).

In the context of RAM, the teen with AD/HD meets stimuli/input in a compromised Adaptation level. The Regulator neural function and Cognator/emotive coping mechanisms are inadequate to adapt in Physiological, role function, interdependence, and self concept/group identity effector behavior modes and the output from the teen is an (-) Ineffective Response.

Roy (1993) stated that specific medical problems may arise specific to age groups and consideration must be given to the person’s physiological and psychosocial developmental stage and sense of self/personality. Roy referred to Erikson’s
psychodynamic theory of human development in reflecting on the individual and creating adaptation within their developmental stage (Wadensten, 2003). The developmental theory of Erikson provides insight into the adolescent struggle to attain adulthood. defines the adolescent stage as a review of the adolescent’s sense of trust, autonomy, initiative, and industry in *Learning Identity vs. Identity Diffusion (Fidelity)*. Erikson's Adolescent stage’s (12-20 years) concept or basic attitude is the coherent sense of self; plans to actualize one’s abilities with feelings of confusion, indecisiveness, possibly antisocial behavior (Wadensten, 2003).

**TABLE 4: RAM Model for Person**

Input → Control Process → Effectors → Output →

<table>
<thead>
<tr>
<th>Stimuli</th>
<th>Coping Mechanisms Of:</th>
<th>Behavioral Modes:</th>
<th>(+)Adaptive and effective responses or (-)Ineffective responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adaptation level (integrated, compensatory, and compromised)</td>
<td>Regulator-neural, Endocrine and Chemical channels Cognator/emotive-Perception, Learning, Judgment, Emotion</td>
<td>-Physiological function -Self-concept -Role function -Interdependence</td>
<td></td>
</tr>
</tbody>
</table>

The adolescent sense of identity is preoccupied with self-image with a connection between future role and past experiences. Many adolescents repeat the crisis resolutions of earlier years to integrate these past elements and establish a lasting ideal of a final identity. Passage through adolescence is recognized as sometimes filled with tumultuous
stress (Wilson & Kneisl, 1992). This period is filled with profound change biologically, socially, and psychologically in the individual as well as role changes within the family and environment (Decker, 2000).

The following literature review is categorized within Roy’s four effector behavioral modes of Physiologic-physical, Role function, Interdependence, and Self-concept/group identity. The review reflects the basis for designing the interview questions (see Appendix D) in the proposed study perceptions regarding adaptation to their AD/HD, including decision-making about taking prescribed AD/HD medications.

Physiological-Physical Mode and AD/HD

The physiological-physical mode includes: Five needs-oxygenation, nutrition, elimination, activity and rest, protection four complex processes-senses; fluid, electrolyte, and acid-base balance; neurological function; endocrine function. For AD/HD, neurological function is the key.

The exact causes of AD/HD remain illusive. Currently, most research suggests a neurobiological basis with inheritance appearing to be an important factor (USDHSS, 1998; Brown, 2000; Biederman, 1998). The neurobiological hypothesis focuses on neurotransmitters, especially catecholamines. This conclusion comes from the positive effect derived from pharmaceutical treatment to increase dopamine release or inhibit reuptake of neurotransmitters. This suggests deficits in the neurobiological system. Some experts suggest a deficit in neuropathways. Even though a diagnostic test for AD/HD does not exist, Goldman, Genel, Bezman, et al (1998) and the Council on Scientific Affairs, American Medical Association, stated, “Diagnostic criteria for AD/HD are based
on extensive empirical research and, if applied appropriately lead to the diagnosis of a syndrome with high interrater reliability, good face validity, and high predictability of course and medication responsiveness.”

The chart (Figure 1) will help organize thought about how the teen responds to AD/HD in the physiological mode:

FIGURE 1: Physiological Mode and Teens with AD/HD

<table>
<thead>
<tr>
<th>Input stimulus</th>
<th>Physiological effector mode</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>Input stimulus is received in a compromised adaptation level related to AD/HD</td>
<td>Regulator coping mechanisms are inadequate in neural, endocrine and chemical channels within the Physiological Mode</td>
<td>Action is an (-) ineffective response to physiological stimulus</td>
</tr>
</tbody>
</table>

A number of central nervous system structural and functional imaging studies also have demonstrated differences between the brains of AD/HD persons and the brains of matched control subjects (Zametkin & Liotta, 1998). To date, no hard, biological measures such as lab tests or radiological studies are available to confirm a diagnosis of AD/HD. Like that of other mental disorders, diagnostic criteria are met through a history and by conducting behavioral assessments (Silver, 2004).
For many, the stimulant medications dramatically reduce their hyperactivity and impulsivity and improve their ability to focus, work, and learn. These medications do not alter learning disability, if present, but do allow the child with AD/HD to have more cognition availability for learning. The medications may also improve physical coordination, such as that needed in handwriting and in sports. The psychostimulant drugs come in long- and short-term forms. Methylphenidate is the most used stimulant for attention disorders (Selekman & Snyder, 1996; NIMH, 2003). Scheres (2003) found in her study of 23 boys with AD/HD an increased inhibitory control with methylphenidate compared to a placebo. Newer long-acting medications seem to promise increased compliance to the medicine regimen and hence more effective control of AD/HD symptoms and overall better health outcomes. McGough (2005) reports long acting Adderall XR to be tolerated and effective. The newer sustained-release stimulants can be taken before school and are long lasting so that the child does not need to go to the school nurse every day for medication. About one out of ten children is not helped by a stimulant medication. Other types of medication may be used if stimulants do not work or if the AD/HD occurs with another disorder (NIMH, 2003). Some physicians attest that early intervention helps prevention of personality disorders (ODD, CD) due to the chemical instability in these neuropathways (Griffin, 2004).

The National Institutes of Mental Health Booklet describing AD/HD (2003) states that stimulants do not make the child feel high, although some children say they feel different or funny (NIMH, 2003). McNeal, Roberts, and Barone (2000) studied the perceptions about medication in mothers and their children with AD/HD (n=31
mother/child pairs). Questionnaires assessed their knowledge and perceptions of stimulant medication and their level of perceived side effects associated with taking this medications. Children tended to view their medications as less beneficial than their mothers and demonstrated significantly less knowledge about their medications than their mothers. While this study measured the knowledge of children with AD/HD and their medications the proposed study of perceptions regarding adaptation to their AD/HD, including decision-making about taking prescribed AD/HD medications will contribute to the knowledge base regarding the experience and perception of teens.

*Role Function Mode and AD/HD*

Roy’s role function mode includes: Need of psychic and spiritual integrity so that one can be or exist with a sense of unity, meaning, and purposefulness in the universe. For teens, a high priority is their role function as a student.

Children with AD/HD may receive stimulation adequately but have a breakdown in the integrative processing demonstrating difficulties retrieving and using information accurately (Figure 2). Difficulties may be in areas of: sequencing data or parts of a story; understanding concepts of time and space, parts and whole, and cause and effect; organization of thought and planning; slowness of speed with processing problem solving; analysis and abstract thinking; or processing environmental input (Kutscher, 2004). While attention disorders, with or without hyperactivity, are not considered learning disabilities themselves, inattention problems can seriously interfere with school role performance and often accompany academic skills disorders (Selekman & Snyder, 1996).
A quasi experimental study with preadolescents (n=65) with ADD or AD/HD was done by Frame, Kelly, and Bailey (2003) of Rutgers University using the Frame Model of Preadolescent Empowerment intervention rooted in Roy’s Adaptation Model, Harter’s Developmental Perspective, Murrell-Armstrong’s Empowerment Matrix. The Frame model is a means of enhancing the self-perceptions of children with AD/HD. She implemented the Frame Model in a school nurse facilitated support group meeting twice a week for 4 weeks supporting increased perceptions of scholastic competence, social acceptance, behavioral conduct, perceived athletic competence, perceived physical appearance, and perceived global self-worth. A pre/post intervention completion of Harter’s Self-Perception Profile for Children found that the participants in the support group had increased scores on each of the six subscales with significant increase in four subscales of perceived social acceptance, perceived athletic competence, perceived physical appearance, and perceived global self-worth. This study used to determine perception of self-worth and found that the intervention was positively associated with perception of self-worth. Although this study did not use open-ended questions to discover the subjects experience in their own words Frame found that perceptions can be defined and measured using the Harter’s Developmental Perspective.

Meaux and Chlonis (2003) studied perception of time comparing children with AD/HD (n=60) versus a control group (n=30) aged 9-12 years of age. Children were asked to watch a light and verbally estimate how long the light was on and then hold a lever down for the same about of time they thought the light was on. Each child participated in 16 light trials of 3, 6, 12, or 24 seconds for a total of 64 light trials.
Children with AD/HD had significantly greater absolute discrepancy scores (F(1,58)=10.8; P<.01) on the time reproductions task than children of the control group. The conclusion was that children with AD/HD have impaired time perception compared to children who do not have AD/HD. These finding of poor time perceptions would affect adaptive life behaviors in all areas in school including schedules, deadlines, health consciousness, and school safety.

FIGURE 2: Role Function Mode in Teens with AD/HD

<table>
<thead>
<tr>
<th>Input stimulus</th>
<th>Role Function Effector Mode</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>Input stimulus is received in a compromised adaptation level related to AD/HD</td>
<td>Cognator coping mechanisms are inadequate in perception, learning, judgment, and emotion within Role Function Mode</td>
<td>Action is an (-) ineffective response to school function</td>
</tr>
</tbody>
</table>

Hoza, Pehham, Dobbs, Owens, and Pillow (2002) from the Department of Psychological Sciences, Purdue University, compared 195 boys with AD/HD and 73 boys in a comparison group (M=9.83 years of age, sd=1.30) regarding positive illusory self-concepts with emphasis on level of aggression, academic achievement, and depression. Boys with AD/HD overestimated relative to teacher report in scholastic
comparatively, social acceptance, and behavioral conduct domains compared to the control group. Further examination by co morbidity subgroups suggested that aggressive and low-achieving boys with AD/HD overestimated their competence the most in the domains in which they experience the most impairment. The proposed study will reflect the original personal responses of the teens about their life experience as a student (role function) and management of their AD/HD.

Interdependence Mode and AD/HD

Roy’s interdependence mode includes: Need is to achieve relational integrity using process of affectional adequacy (i.e., the giving and receiving of love, respect, and value through effective relations and communication.) Social acceptance is a key life skill for teens in developing relationships with friends and family.

Before diagnosis of AD/HD, families are confused, concerned, and anxious as to why their child is having difficulties. Children with AD/HD may or may not be in a loving family that understands their special needs. Parents typically give more commands, directions, and supervision to children with AD/HD than the other siblings (Selekman & Snyder, 1996). Siblings may resent the amount of time and attention paid to the child with special needs and the embarrassment that their sibling often causes them. Although there may not be a difference in the incidence of AD/HD across cultures, culture may play a role in how children with AD/HD develop social competence with family, friends/peers, and communities (Houck, et al, 2002).

The impulsivity and lack of control that is exhibited in AD/HD does not foster easy interdependence. The challenges facing families disrupted by AD/HD are often
overwhelming (Kendall, 1998). *Interdependence* is a work in progress as parent and child begin to accept this challenge and work toward adaptation through treatment. Family adaptation is achieved when its members modify behavior to each other and to their outer world as the situation demands (Freidman, Bowden, & Jones, 2003). Roy’s theory stresses health promotion with nurse interventions that assist clients in manipulating their environment, consistent with environmental-family interactions.
Hoza, Pehham, Milich, Pillow, and McBride (1993) compared the self-perceptions and attributions of boys with AD/HD (n=95) and a control group (n=73). The boys with AD/HD viewed themselves as no worse than control boys with self-perceived competence and global self-worth, especially when internalizing symptomatology was taken into account statistically through covariance analyses. The boys with AD/HD were more likely to take responsibility for social successes and less likely to take responsibility for social failures than the control boys.

Kendall (2003) studied 39 children and adolescents with qualitative semi-structured interviews asked them to describe themselves, what they believed about AD/HD, who helped them, which treatments they used, and if race, ethnicity, or of
socioeconomic status might affect them. She taped, transcribed, and analyzed for prevalent themes. One theme she found was that the subjects 'parroted back' what they've been told about being a troublemaker, stupid, slow, bad, not like the other kids, or being whacko. Another theme was that the subjects were unable to separate AD/HD from who they were. Kendall found that they had normal emotions with feeling mad, frustration, sadness, and shame as prevalent themes. Most of the children stated the medication helped the most of all the treatments for AD/HD, but they wished they did not need medication. The subjects suffered side effects, did not feel like themselves after taking pills, and felt fear and shame for taking medication. Another finding was the theme of mother love. They loved their mom. Finally, she found that these children with AD/HD know how to behave within the rules but they are unable to do what they know to do.

Teens often experience some level of functional impairment at home and at school (NINDS, 2003). Ellison (2003) uses the argument that adolescent outcomes of teens with AD/HD show that they are more likely to experience sexually transmitted diseases and teen pregnancies, have fewer friends, have increased incidence of depression and personality disorders, and participate in more antisocial responses than children without AD/HD which may enforce the validity of the disorder. Exploration to elicit teen perceptions of life experience for self, family, friends/peers, and communities and how these perceptions have changed over time is essential for assisting teens in promotion of actions with (+) adaptation with effective responses.
Self-concept/group identity mode is the composite of beliefs and feelings that one holds about oneself at a given time, formed from internal perceptions and perceptions of other’s reactions, and directing one’s behavior. Teens with AD/HD must set forth great effort in the adolescent development of self-concept.

One needs to know who one is so that one can be, or exist with a sense of unity as it relates to internal perceptions of psychic integrity, physical integrity, personal characteristics, ideals and expectancies, moral-ethical-spiritual standards, learning, the inner cell of the self, and self-esteem. These self-perceptions are formed from internal and external reactions between self and others (Roy, 1993).

Quinn and Wigal (2004) found in their National Online Survey that many parents (n=541) they interviewed online responded that AD/HD affects a child’s self-esteem a great deal, regardless of the child’s gender. In their online survey of children with AD/HD (n=346) aged 12-17 years of age, Quinn & Wigal found that 9% of the boys and 15% of the girls report that they felt worse after being diagnosed with AD/HD with the remainder feeling about the same or better.

Dumas and Pelletier (1999) found that self-perceptions were lower among children with AD/HD than among children in a control group in five of six categories studied (p=0.0001). Self-perceptions were studied among hyperactive children (n=57; 20 girls: 37 boys) in comparison with a general population of children (n=59; 25 girls: 34 boys) the same age (6-11 years of age). The six categories studied were scholastic competence, social acceptance, athletic competence, physical appearance, behavioral...
conduct, and global self-worth. The only dimension that AD/HD children showed higher self-perception was athletic competence. The general population was recruited from a Quebec City elementary school and the hyperactive children were being treated at an outpatient clinic of a children’s psychiatric hospital. The children in both groups participated in an interview answering the Self-Perception Profile for Children \( (r=0.90) \) consisting of the six defined subscales. Multivariate analysis (MANOVA) indicated that the dimensions of scholastic competence, social acceptance, and behavioral conduct were areas presenting problems for hyperactive children. This work confirms the precept that insight into the specific perceptions of teens is an important inroad to a comprehensive plan of school nursing care. Use of the Self-Perception Profile for Children is a structured measurement while the proposed study is an open-ended question design encouraging new revelations into the perceptions of teens with AD/HD.
Krueger and Kendall’s (2001) *Descriptions of self: an exploratory study of adolescents with AD/HD* concluded a primary hypothesis that development of self in teens with AD/HD has been disrupted by the neurobiology of AD/HD as well as the cumulative effect of the stigma of AD/HD and negative appraisals given by society. Constant comparative analysis of both individual and focus group interview data with adolescents (n=11; 3 girls: 8 boys) with AD/HD found that the adolescent’s perception of self was distorted. Unable to separate their definition of self from the disorder,
adolescents took on an identity of self that integrated and defended difficulties in school
work, getting along with family and peers, frustration, depression, and feeling
misunderstood, lost, and angry. They did not have a consistent sense of self in time and
difficulty reinstating stability after losing control of emotions and behaviors. This study
concluded that therapeutic intrapsychic psychotherapy with attention to function of self is
important to stabilize and give order an adolescent’s sense of self. This study calls for
further exploration on the development of self in children and youth with AD/HD. The
proposed AD/HD study gives themes and sub themes about perceptions of self-concept/group identity in teens with AD/HD.

Danckaerts, Heptinstall, Chadwick, and Taylor (1999) investigated the adolescent
interview scale for DSM based AD/HD symptoms. This study concluded that well
validated instruments for self-report of attention deficit and hyperactivity disorder are
lacking while research on AD/HD in adolescence relies on self-report. The results for
validating the adolescent interview scale for DSM show that this measure has a high
inter-rater reliability and is a good predictor of general outcome but adolescents do not
self-report symptoms of AD/HD with validity. This study throws doubt on the validity of
response to formatted questions. The open-ended question qualitative design of the
proposed study may discover an insight into the true beliefs and feelings that motivate
teen responses.

Summary

Teens with AD/HD have a body system that is inadequate to maintain and
function within a state of equilibrium and adaptation. The literature demonstrates that
while many studies measure the knowledge of children with AD/HD and their medications with formatted instruments there has been doubt on the validity of response to formatted questions. The proposed study of perceptions regarding adaptation to their AD/HD, including decision-making about taking prescribed AD/HD medications will reflect the original personal responses of the teens about their life experience in regards to management of their AD/HD and medications and how these perceptions have changed over time. The qualitative design of the proposed study with open-ended questions may provide insight into the beliefs and feelings that motivate teen responses to treatment. This new knowledge will inform teens, families, schools, and healthcare providers for promotion of newly designed optimum treatment interventions and (+) Adaptation to AD/HD.
CHAPTER THREE

Methodology

This chapter contains a description of the research design and methodology for the study of teens’ perceptions about AD/HD medications and adaptation to AD/HD, including decision-making about taking prescribed AD/HD medications. This chapter will include information on study sample, protection of human subjects, subject recruitment, data collection, data analysis, and trustworthiness.

Research Design

This was a qualitative study of teen’s perceptions about AD/HD medications and adaptation to AD/HD. Data were gathered using semi-structured interviews organized a priori according to Roy’s four modes of adaptation: Physiological mode, Self-concept mode, Interdependence (family and friends) mode and Role function (student) mode. (Roy, 1993). Transcriptions of audio taped interviews were analyzed inductively for sub themes within each mode of adaptation and an overarching main theme was then derived from the sub themes.

A qualitative design was considered appropriate as little is known about the perceptions of teens about their AD/HD particularly regarding the newer AD/HD long acting medications such as Strattera, Concerta, Adderall XR (Mayring, 2000; Lobiondo-Wood & Haber, 2002; Polit & Hungler, 1989). However, the design incorporated elements of content analysis: use of a priori categories (Roy’s modes of adaptation) to guide data collection and analysis of text messages (transcribed interviews) to accommodate both etic (a priori categories) and emic (participants’ own words)
perspectives. Neuendorf (2002) supported this derived etic approach in content analysis as a necessary and useful pre requisite to formal content analysis in some cases:

“When existing theory or research literature cannot give a complete picture of the message pool, the researcher may take a more practical approach. The researcher may need to immerse himself or herself in the world of the message pool and conduct a qualitative scrutiny…” to identify emergent variables (p. 102-103) for subsequent study.

Denzin and Lincoln (2000) noted that content analysis may “obscure the interpretive processes that turn talk into text” (p.640) and so supported a more flexible, interpretive approach to analysis of transcribed (textual) interviews.

The review of literature about teens with AD/HD provided direction in terms of areas of potential stress among teens and use of Roy’s modes of adaptation as general a priori conceptual categories for the study. However, there was insufficient understanding reported in extant literature about teens’ own perceptions to guide specific variables for a quantitative study. Hence, a hybrid qualitative study design with selected elements of content analysis was considered most appropriate to acknowledge existing knowledge and still solicit qualitative data regarding teens’ subjective perceptions of their experience with AD/HD.

Sample

Fifteen students were interviewed with open-ended questions. Criteria for participation were that the teen: a) be a student at selected public high school, b) be age 14-17 by August 12, 2004, c) have parental permission for this researcher to invite the teen to participate in the study, d) consent to participate, e) be able to understand and
respond to the interview questions, and f) be taking medication for AD/HD. These criteria include male and female teens of all ethnicities as eligible for participation. This data was determined between this investigator and the respondents to the Parent Letter inviting participation in the study.

Protection of Human Subjects

This study was approved by representatives of the University of Arizona College of Nursing, submitted to, and approved by the University of Arizona Institutional Review Board (Appendix E). A thorough explanation of the consent form was exchanged between the PI and the parent/guardian and teen participants with opportunity for questions and answers before proceeding. Careful attention was given to confidentiality through pseudonyms chosen by the teen participant. All collected data was filed under pseudonyms with no identifiers to the real identity of the teen. Audiotapes were destroyed by cutting tapes upon transcription by the PI. Audiotapes and transcriptions were stored under lock and key at PI’s office.

The parent/teen consent form (Appendix A) included assurances that the teen could stop the interview at any time at his/her discretion without any hard feelings. In particular, teens were assured that their care at the school nurse office would not be affected in any way by their decision to participate or not to participate in the study. In addition, other staff at the high school would have no knowledge about who participated in the study. Participation in this study should not affect the schoolwork in any way.
Subject Recruitment

This study was conducted with a sample of teens whose parents report AD/HD in a public high school where this graduate student researcher was employed as the school nurse. Approval was obtained from the Public School District Assistant Superintendent, (Appendix C) and from the Principal at the high school (Appendix F). A letter of invitation (Appendix B) with consent form (Appendix A) was mailed to potential participant’s parents. PI explained the study to respondents and obtain signed parent/teen consent as well as demographics of gender, age, medications, and duration of medications (Appendix I). The interview was conducted immediately. The open-ended interview questions were organized in categories (consistent with content analysis) as follows:

Interview guide: (Organized using Roy’s Four Modes of Adaptation (Physiological, Role Function, Interdependence, and Self-concept/group identity):

I. Tell me about your experience with being diagnosed with ADD or AD/HD:
   Prompts: “How old were you”? What was going on at that time? What did you think and feel about it all?

II. Physiological Mode: (Taking/ not-taking medications):
   a. When you first started taking medication, how did you feel?
   b. Do you remember what medications you took?
   c. How did it feel to take the medications?
   d. What is it like now?

III. Role function Mode: (experience as a student):
   a. What has it been like for you at school?
   b. What effect do you think taking medications has had on your school work?
   c. What else do you do to manage your school experiences?
IV. Interdependence Mode: (family & friends):
   a. What is it like for you with your family regarding having AD/HD & taking medications?
   b. Has this changed over time, as you got older?
   c. What has it been like for you with your friends, with having AD/HD & taking medications?
   d. How do you handle this part of your life with your friends?

IV. Self-Concept Mode (Perceptions of self):
   a. How would you describe yourself? Your personality?
   b. Has having AD/HD and taking medication affected how you think of yourself?

V. Wrap – up: Opportunity for teen to add anything that s/he may want to say.
   What else can you tell me about your experience with having AD/HD, and taking medications or not?

Data Collection

The interview was conducted at a convenient time determined by the parent and the teen after school hours at either the home or school. Participants were asked to recall and express experiences with AD/HD and their AD/HD medications presently, in the past, and as anticipated in the future (Appendix D). The interview was recorded on an audiotape recorder for future transcription and analysis identified anonymously by a pseudonym chosen by the teen. Three of the teens were invited to participate in a follow-up interview to ask whether s/he agrees with the results of the study.

Data Analysis

Audio taped interviews were transcribed into written format (text) and rechecked for accuracy. The audiotapes were then cut up and destroyed. Participants’ responses were analyzed in each mode of adaptation. The outcome of data analysis was a taxonomy of identified theme and sub themes of perceptions regarding adaptation to their AD/HD,
including decision-making about taking prescribed AD/HD medications within the four Modes of Callista Roy’s Adaptation model (RAM) (Roy, 1993): 1) physiological, 2) role function, 3) interdependence, and 4) self-concept.

**Assumptions**

1. Roy's Adaptation Model provides an appropriate theoretical context for learning teens' perceptions of physical/physiological, role function, interrelationships, and self-concept in relation to being diagnosed with AD/HD.

2. AD/HD is a legitimate psychiatric disorder as found in the diagnostic criteria of the American Psychiatric Associations Diagnostic Manual (APA, 2000).

3. Power differential exists between the teen and school nurse that may influence teen's willingness to share their perceptions regarding AD/HD.

4. The investigators' past experience and knowledge of AD/HD medications and their benefits and potential side effects may influence her interpretation of interviews.

5. Teens are able to express their perceptions regarding AD/HD medications and AD/HD.

6. Thinking and feeling mediate human action.
FIGURE 5: Data Analysis (Mayring, 2000)

Step 1

Audio taped interviews of open ended questions allow teens to describe their experiences with AD/HD

Step 2

Preliminary data analysis for sub themes in each mode

Step 3

Follow-up interviews to conduct “member checks” (ask whether they agree with the preliminary results of the study) to ensure trustworthiness of study findings, and to seek clarification of data gathered in the first interview were conducted on some teens.

Step 4

The outcome of data analysis was a taxonomy of theme and sub themes related to teens’ perceptions of managing their AD/HD, including decision-making about taking medications prescribed for AD/HD within RAM modes of:

1) physiological
2) role function
3) interdependence
4) self-concept

Step 5

Formative check of reliability with faculty advisors within the University of Arizona College of Nursing.

Step 6

Interpretation of results with quantitative steps of analysis (frequencies)

Step 7

Summative check of reliability, transferability, saturation, and scientific rigor with faculty advisors within the University of Arizona College of Nursing.
Trustworthiness

Follow-up interviews to conduct “member checks” (ask whether the teens agree with the results of the study) to ensure trustworthiness of study findings, and to seek clarification of data gathered in the first interview was conducted on some teens. The findings of the study were reviewed, clarified, and approved by the principal investigator's University of Arizona College of Nursing Thesis Committee.

Summary

This chapter gives a description of the methods used in this qualitative research study. A qualitative research design using content analysis of open-ended interview questions was used to discover teens’ perceptions regarding adaptation to their AD/HD, including decision-making about taking prescribed AD/HD medications. These data were preserved in a taxonomy of themes and sub themes organized using Callista Roy’s Adaptation Model (1993) with modes of 1) physical, 2) role function, 3) interdependence, and 4) self-concept.
CHAPTER FOUR

Data Analysis and Presentation of Findings

This chapter presents results of analysis of interviews with teens about their perceptions about adapting to a diagnosis of AD/HD using content analysis. A description of the study participants is presented first, followed by review of the coding process used in content analysis of the interviews. Next, themes are organized within the four modes of Roy’s Adaptation Model: 1) physiological, 2) role function, 3) interdependence, and 4) self-concept/group identity.

Sample

Study participants were recruited from a local public high school with grade 9-12. Criteria for participation were that the teen be: a) a student at CDO, b) age 14-17 by August 12, 2004, c) parents give permission for the PI to invite their son or daughter to participate in the study, d) student gives consent to participate, e) student has the ability to understand and respond to the interview questions, and f) student must be taking medication for AD/HD. These criteria include male and female students of all ethnicities as eligible for participation.

Fifty-three invitations to participate in the teen interview were sent to parent/guardians who reported ADD or AD/HD to the school nurse. Fifteen parent/guardians allowed the PI to meet with them and their teen to explain the study and obtain teen consent. All fifteen teens were eager for someone to listen to their experience with AD/HD medications.
Five girls and ten boys volunteered to participate, after their parents had given permission for the researcher to invite them to join the study. Two participants were in 9th grade, nine were in 10th grade, two were in 11th grade, and two were in 12th grade. Additional descriptive data was gathered to provide a context for the interviews: diagnosis as either ADD or ADD/HD, age at diagnosis, length of time since diagnosis, prescription medications for ADD or ADD/HD, any co-morbidities,

Six teens had diagnoses of AD/HD-Inattentive type, five teens were diagnosed with AD/HD-Hyperactivity type, and four teens were diagnosed with AD/HD-Combined type. Six teens were diagnosed at 6 years, three were diagnosed at 7 years, and one teen for each age of 8, 9, 10, 11, 12, and 14 years old. The original diagnoses were made by pediatricians (n=8), psychiatrists (n=3), psychologists (n=3), and a neurologist (n=1).

Most teens (73%) remembered their age at diagnosis accurately within one year. Sixty percent of the teens were age nine and under when diagnosed. Seventy-three percent were ten and under while 87% were twelve and under.

All of these teens were on medication including: Adderall (n=4 Adderall XR; n=1 Adderall, not time released), Concerta (n=5), Ritalin (n=2), Dexedrine/dextrostat (n=1), Clonidine (n=1), and Strattera (n=1). The teens had been on these meds in years ranging from 1-9 years. Comorbidities included depression (medication-Prozac), epilepsy (Depakote, Trileptal), bipolar and reactive attachment disorder (Risperdal & Clonidine), and the learning disability, dysgraphia-extremely poor handwriting.
Data Collection

Interviews were conducted in private settings in the student's home with parents in another part of the house. Each interview lasted 30-50 minutes, depending on the length of the descriptions of their perceptions. Teens chose pseudonyms from letters A-O that fell chronologically to that interview (i.e., the teen interviewed first chose a pseudonym starting with the letter A (Amy), the second teen chose a pseudonym starting with letter B (Bejezuz), and so on.) Interviews were audio taped and later transcribed verbatim by the researcher, using the selected pseudonyms. The underlying theme and sub themes were identified using content analysis of the interview transcripts. Marylyn's apriori categories/themes

Presentation of Findings

After collecting general demographic information and other background information (above), the first question was, “So, what was going on at the time you were first diagnosed?” Eight teens remembered perceptions of trouble at school, while only one teen remembered trouble at home. One teen remembered going to many doctors. When asked, "What did you think or feel about it all?", four did not remember and one was indifferent and said, "It didn't matter to me.” The remaining ten were divided evenly with positive and negative remembrances, with five feeling that it was "OK," or fine. Five remembered anger, unhappiness, being tired, and even feeling pointless.

The next sets of questions were organized and analyzed to correspond with the RAM modes of adaptation. Themes were organized within the four modes of RAM as
follows: 1) physiological; 2) role function; 3) interdependence; and 4) self-concept.

Paragraphs following the tables include explanation of the data.

**Physiological-Physical Mode (Taking/not-taking medications)**

The physiological mode questions focused on regulator coping mechanisms that are inadequate in neurochemical channels within the physiological mode. The main sub theme for this section is: Many teens felt that they were the same as anyone else when taking medications. The tables and narratives presented in this section illustrate the data used to derive the sub theme the physiological mode.

**TABLE 5: First Taking Medications**

*When you first started taking medications, how did you feel?*

<table>
<thead>
<tr>
<th>Positive (n=3)</th>
<th>Negative (n=9)</th>
<th>Indifferent (n=2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Concentrate better.</td>
<td>Do I have to?</td>
<td>No feelings – I just took it (meds).</td>
</tr>
<tr>
<td>I wanted it to work.</td>
<td>What is it doing to me?</td>
<td>Never able to notice anything tangible.</td>
</tr>
<tr>
<td>Makes me want to work.</td>
<td>Headaches/irritable.</td>
<td>Felt like there is nothing that happened.</td>
</tr>
<tr>
<td>Listen to teacher.</td>
<td>Tired/worn out</td>
<td></td>
</tr>
<tr>
<td>Less distracted.</td>
<td>Out of control until they got the meds right.</td>
<td></td>
</tr>
<tr>
<td>Less time for teacher to explain.</td>
<td>Loss of appetite – the meds helped me concentrate but not eating made me have a hard time concentrating so meds weren’t effective.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Meds at school was a hassle.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Concerta took away social skills.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Uncomfortable.</td>
<td></td>
</tr>
</tbody>
</table>
When asked how the teen felt when first taking medications, sixty percent felt negative and twenty percent felt positive. Thirteen percent felt indifferent having no feelings or never able to notice anything tangible. When asked what medicines the teen took at first diagnosis, four did not remember. Nine of the 15 remembered taking Ritalin and two remembered taking Adderall. "It was annoying! Every day having to take it." (Elizabeth, p. 22, line 26).

While unable to remember some of the questions about their first feelings when diagnosed, every teen remembered how it felt to take the medications. The memories were more positive (60%) than negative (20%). "All right, I guess as long as it will help me I am fine with it" (Clayton, p. 13, line 2). Three teens (20%) felt the same and did not really feel much different when taking medications.

### TABLE 6: How did it Feel?

<table>
<thead>
<tr>
<th>How did it feel to take the medications?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive (n=9)</td>
</tr>
<tr>
<td>No hyperactivity with slow released Adderall</td>
</tr>
<tr>
<td>Fine as long as it helps.</td>
</tr>
<tr>
<td>I feel like any other person.</td>
</tr>
<tr>
<td>Meds helped school but no social interaction.</td>
</tr>
<tr>
<td>Ritalin was fine but with Concerta and Dexedrine, it just sucked.</td>
</tr>
<tr>
<td>Concentrate much better.</td>
</tr>
<tr>
<td>A good thing.</td>
</tr>
<tr>
<td>Concerta 32 mg worked.</td>
</tr>
<tr>
<td>Enjoyed going to the nice school nurse.</td>
</tr>
<tr>
<td>I didn’t have a problem with it.</td>
</tr>
<tr>
<td>Negative (n=3)</td>
</tr>
<tr>
<td>Annoying</td>
</tr>
<tr>
<td>Didn’t like it.</td>
</tr>
<tr>
<td>Hassle.</td>
</tr>
<tr>
<td>Tired/sleepy.</td>
</tr>
<tr>
<td>The same (n=3)</td>
</tr>
<tr>
<td>Didn’t really feel much different.</td>
</tr>
<tr>
<td>Didn’t feel anything.</td>
</tr>
<tr>
<td>No reaction to it – I just kept being hyper, it didn’t help.</td>
</tr>
</tbody>
</table>

...
Ten teens (67%) responded positively and 20% responded negatively when asked to "Tell about what it is like now to take medications." "It is kinda like, you know, when you take vitamins. You feel like you are helping yourself" (Amy, page 2, line 13). "I take it only once in the morning. I don't have any problem with it" (Orchid, page 74, line 20-21). Twenty percent were indifferent with such responses as: "Pretty much exactly like it always is." "It's just what I am used to" (Bejezuz, page 6, Line 45).

Teens perceptions of AD/HD and taking or not taking medications were memories of hard times adapting to and taking medications. Over time teens learned the value of medications and developed feelings of being the same as anyone else when on medications. Medication made them equal and their AD/HD was unknown to others. The sub theme of Physiological mode is: "Medications are a hassle but they work."
TABLE 7: What is it Like Now?

<table>
<thead>
<tr>
<th>Positive (n=10)</th>
<th>Negative (n=3)</th>
<th>Indifferent (n=2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Helping yourself</td>
<td>Still don’t like to take meds but I know I have to.</td>
<td>Same as always.</td>
</tr>
<tr>
<td>I’m used to it.</td>
<td>I hate taking meds.</td>
<td>What I’m used to.</td>
</tr>
<tr>
<td>I don’t NOT take meds.</td>
<td>They still have a hard time getting me to take meds.</td>
<td>Mom says they help but I don’t think so, but OK.</td>
</tr>
<tr>
<td>It helps – I take meds</td>
<td>Don’t feel anything.</td>
<td>Nobody knows at school.</td>
</tr>
<tr>
<td>When I take meds, I’m normal.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Concentrate better.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Listening and getting more information out of what I am listening to.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Easier to get started on a project.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Everybody takes meds – I feel like just any other person.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pay attention.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>It’s good.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Able to memorize.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Everything’s better.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Keep my mind from wandering.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I do homework.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Meds got me good grades.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fine.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Don’t have any problem with it.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Take it only once in the morning.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**Role Function Mode (role as student and family member)**

The Role Function mode interview questions focused on inadequate cognator coping mechanisms in areas of: perception, learning, judgment, and emotion. The sub theme for this section is: Teens with AD/HD are the same as everyone else but with a slight imperfection or a gift. The tables and narratives presented in this section illustrate the data used to derive the sub theme the role function mode.

The investigator asked what it has been like at school and the teens were very positive (73%) but mixed with negative when discussing school without medicine. "I had a computer class last year, actually, where if I didn't take it (meds), then it would take me forever to do my assignments. Cuz we had to type and I had …I don't know how to tell you…if I took it (meds) I would get to work cuz I would be concentrating on what to do and stuff" (Mo, page 61, line 32).

**TABLE 8: What Effect Medications has on School Work?**

<table>
<thead>
<tr>
<th>Positive</th>
<th>Negative</th>
</tr>
</thead>
<tbody>
<tr>
<td>Finally turning stuff in.</td>
<td>I do work sometimes but it kind of messed it up a little.</td>
</tr>
<tr>
<td>Big plus!</td>
<td>Meds made me sleepy and grades go down.</td>
</tr>
<tr>
<td>Teachers are: more nice, know I pay attention, and know I care and that helps.</td>
<td>Nothing.</td>
</tr>
<tr>
<td>Good.</td>
<td></td>
</tr>
<tr>
<td>Major effect!</td>
<td></td>
</tr>
<tr>
<td>Grades fell when off meds.</td>
<td></td>
</tr>
<tr>
<td>I can focus on problems and writing.</td>
<td></td>
</tr>
<tr>
<td>I can channel by brain, I don’t wander off and do other things.</td>
<td></td>
</tr>
<tr>
<td>Increased concentration.</td>
<td></td>
</tr>
<tr>
<td>Get more out of what I listen to.</td>
<td></td>
</tr>
<tr>
<td>It is a lot easier.</td>
<td></td>
</tr>
<tr>
<td>It’s helped it all gradually.</td>
<td></td>
</tr>
<tr>
<td>Higher test scores.</td>
<td></td>
</tr>
<tr>
<td>Definitely a positive effect!</td>
<td></td>
</tr>
</tbody>
</table>
Many teens felt they were the same as anyone else when on medication. Medication made them equal and made their disorder unknown to others. Some teens spoke about having learning disorders (LDs) and seemed to separate the LD from the AD/HD. All of the teens were acutely aware of their feelings about school and had dealt with AD/HD and school and come to a conclusion about their performance as either positive or negative. At this stage in their lives they have learned about themselves and AD/HD and are not just unconsciously moving though life. School function is important to them.

When the investigator came to this question the teens were animated about their answers. The discussion of medication and school struck a vigorous response and for the most part the response was strongly positive (80%). "Well, it's definitely helps if I take it. If I don't take it I get ineligible for football or soccer" (Mo, page 63, line 41). These students were emphatic that finding the proper medications had drastically improved their schoolwork in areas of: desire to work, concentration/focus, learning, test taking, and interpersonal interaction.

The negative (20%) responses were from three boys that felt that medication had no merit for meds at school. The schoolwork was not improving for two of the boys because they felt the medication side effect of fatigue was clouding their performance. "Some makes me like sleepy and stuff so… I was doing really good before I started taking this pill called Clonidine, which makes you tired. My grades have decreased and stuff, but that is not the only reason. I don't think it has affected it in any other way" (David, page 17, line 41). One boy was refusing to believe that medication had any good
effect even though his mother and teachers reported improved behaviors to the investigator when he was taking medication. He was unable to see it, however, he did say in the wrap up last question at the end that he did not NOT take his medications because he knew he needed them and that the medications were good for him.

The investigator asked the teens what else they do to manage their school experience and 27% responded that they do nothing special. The remaining 73% had definite planning and preplanning that they had developed to assist them in good study habits. Lists and planning were the techniques relied upon heavily and organization was also helpful. "I keep that all written down in my planner and when I walk into my math class, there's always the math homework written on the board so I just write that down on the piece of paper I going to be doing it on so I don’t' forget that. And that keeps me organized" (Orchid, page 75, line 13).
TABLE 9: What Else to Manage School?

*What else do you do to manage your school experiences?*

<table>
<thead>
<tr>
<th>Nothing (n=4)</th>
<th>Do anything I want.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Don’t study much I just remember information and recall it.</td>
</tr>
<tr>
<td></td>
<td>Meds kick in and I do what I have to do.</td>
</tr>
<tr>
<td></td>
<td>I just don’t think about it.</td>
</tr>
<tr>
<td>Lists/planner (n=5)</td>
<td>Lists on arms/hands.</td>
</tr>
<tr>
<td></td>
<td>Notes on the wall.</td>
</tr>
<tr>
<td></td>
<td>Work schedules.</td>
</tr>
<tr>
<td>Organize (n=2)</td>
<td>Organize with folders.</td>
</tr>
<tr>
<td></td>
<td>Steps for everything I do.</td>
</tr>
<tr>
<td></td>
<td>Just keep stuff in order.</td>
</tr>
<tr>
<td></td>
<td>I put my things in a stack of what is least important to what is most important to help me get them done in the order they need to be done.</td>
</tr>
<tr>
<td></td>
<td>Turning it in is hard enough but getting it right is another story.</td>
</tr>
<tr>
<td>Train myself to focus and study (n=3)</td>
<td>Train my brain to focus with karate and other things.</td>
</tr>
<tr>
<td></td>
<td>Work while in the classroom because I won’t work outside the classroom.</td>
</tr>
<tr>
<td>Counselors (n=1)</td>
<td>They try to make me better academically.</td>
</tr>
<tr>
<td></td>
<td>I refuse to listen to them.</td>
</tr>
</tbody>
</table>

Three teens actually tried to increase their focus with active self-training techniques. The teen that identified his counselors as a school a part of managing school was very negative about his willingness to listen to them.

Teens' perceptions of AD/HD and taking or not taking medications in role function mode were that teens with AD/HD are the same as everyone else but with slight imperfection or a gift. Take care, use kids own words!!. Medications were perceived to definitely improve school performance and increase learning. As with teens without AD/HD, planning and preplanning with good study habits and organization helps
adaptation to school. The sub theme for the role function mode is: "I do better in school when I take the meds."

_Interdependence Mode (family and friends)_

The Interdependence mode questions focused on cognator coping mechanisms inadequate in perception, learning, judgment, and emotion within the interdependence mode. The sub theme for this section is that teens with AD/HD feel that interactions with family and friends are positive and with medication friends do not know they are any different. The tables and narratives presented in this section illustrate the data used to derive the sub theme the role function mode.

The investigator asked what it is like for you with your family regarding having AD/HD and taking medications and eighty seven percent felt positive about their family interactions. Thirteen of the fifteen respondents spoke of feeling either different (n=7) or the same (n=6) as their family. The teens that felt different also expressed negative family interaction such as: anger, fighting, siblings teasing them, and others having a problem with their AD/HD. Four of the teens (27%) responded that their family also had AD/HD and that they fit right in. "Three out of our four of our family members have ADD. So, it is not that odd for us to be taking medication for it. My Dad is the only one who does not have ADD and I am not sure that animals can have ADD but I really think they have it too. (Laughter). Our whole family, with the exception of our relatives, have ADD. I so its, I guess it adds to the fun. It isn't really a problem for us as a family" (Greg, page 33, line 10).
TABLE 10: Family and AD/HD

*What is it like for you with your family regarding having AD/HD and taking medications?*

<table>
<thead>
<tr>
<th>Positive (n=13)</th>
<th>Negative (n=2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doesn’t really bother me that much.</td>
<td>There’s a lot of fighting about the meds and my AD/HD.</td>
</tr>
<tr>
<td>We are exactly the same-we are all kinda weird.</td>
<td>I didn’t have a problem with it and I don’t know why they did (father denied diagnosis-mother agreed with diagnosis).</td>
</tr>
<tr>
<td>I don’t act any different with my family when I’m on medication.</td>
<td>They were mad I had ADD.</td>
</tr>
<tr>
<td>I doesn’t bother any of us-we all take medications.</td>
<td>My brother doesn’t take meds and makes fun of me.</td>
</tr>
<tr>
<td>Medications help with the family.</td>
<td>My dad and girlfriend gang up on me and tell me ADD is made up I don’t have it.</td>
</tr>
<tr>
<td>My family can tell if I don’t take my meds-I don’t want to stop taking meds.</td>
<td></td>
</tr>
<tr>
<td>A lot of my family has it—it’s kind of a little joke if I don’t take my meds we both feel that mutually we are not paying attention to each other.</td>
<td></td>
</tr>
<tr>
<td>Everyday this I just do-take meds.</td>
<td></td>
</tr>
<tr>
<td>Easy with meds-without meds it’s hell.</td>
<td></td>
</tr>
<tr>
<td>Without meds, I get hyper and my mother gets mad at me.</td>
<td></td>
</tr>
<tr>
<td>I take meds if we go someplace where I need to be calm like to impress somebody like the boss-if meds help I should take them until I get older.</td>
<td></td>
</tr>
<tr>
<td>I don’t think there are any behavioral differences.</td>
<td></td>
</tr>
</tbody>
</table>

The students that felt positive family interaction (n=13) were also the teens that attributed positive results to medications. The two teens with negative feelings about family interactions expressed that there was fighting about meds and also about AD/HD. One mother had to fight to get him to take his medication and he did not perceive that it was worthwhile because he felt that it impaired his social interactions with friends.
Another teen's father refused to admit to the diagnosis of AD/HD. "My dad and his girlfriend were really in denial of it and I didn’t really have a problem with it so I don't know why they did. It was like they were mad that I had it" (Orchid, page 75, line 36). Mother supported the diagnosis and this caused family friction.

When asked if things have changed over time with your family regarding AD/HD and medications 53% felt it has been a positive change over time. These teens seem to be able to accept the AD/HD and work on focusing, calming down, coping, and using the medications to enhance change. "They can tell if I didn't take it (meds) cuz I talk a lot and I yell and scream. I am just not as nice. When I do take it they see a dramatic difference. I mean it makes me feel sad that they think I am so rotten without it. So, it makes me feel better to take it than to not. I take them every day. Summer too" (Elizabeth, page 23, line 10). The teen (n=1) that responded that it had gotten worse attributed it to being a teenager and natural rebellion. Five teens (33%) felt that the family experience has not changed over time.

Thirteen teens (87%) had positive answers when the investigator asked what it has been like for you with your friends, with having AD/HD and taking medications. Most felt with medications friends do not even know that they are different. "Being with my friends, they know I have AD/HD and they know that I take medications. I am always hyper so there is no cause for me to be bothered by having AD/HD" (Loser, page 60, line 4).
TABLE 11: Changed Over Time?

*Has this changed over time, as you got older?*

<table>
<thead>
<tr>
<th>Positive (n=8)</th>
<th>Negative (n=1)</th>
<th>Stayed the same (n=5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accept it.</td>
<td>Gotten worse-I guess that’s part of being a rebellious teen.</td>
<td>No.</td>
</tr>
<tr>
<td>Not worry that I am not normal.</td>
<td></td>
<td>Hasn’t really changed.</td>
</tr>
<tr>
<td>Easier-pay attention more without the meds-I need it for school.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not as mean as I used to be.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I could see meds help me as I got older.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I kinda understand the meds and how I best work when I have meds.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Able to calm down and focus and cope-I get things done.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I make myself calm down by watching TV or playing video games in my room.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The investigator asked how you handle this part of your life with your friends and eleven (73%) respondents feel that they act no differently with friends than any other teenager. "If I it don't think about it then it almost goes away, almost (Amy, page 3, line 30). Two teens felt that meds helped them to focus and control themselves. Two teens felt that being active is how they handled friendships."
TABLE 12: Friends and AD/HD

What has it been like for you with your friends, with having AD/HD and taking medications?

<table>
<thead>
<tr>
<th>Positive (n=13)</th>
<th>Negative (n=1)</th>
<th>Indifferent (n=1)</th>
</tr>
</thead>
<tbody>
<tr>
<td>People don’t know I am NOT different from them because I take meds.</td>
<td>Harder to keep friends-Arguments with friends and their parents.</td>
<td>I don’t think about it-more fun when not on meds.</td>
</tr>
<tr>
<td>Most of my friends have it too but are unmedicated-so we’ll hang out and we’ll be fine.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Friends know I take meds but don’t express an opinion about it-medications makes it easier with friends-it’s no big deal.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Friends don’t really care-they remind me to take my pills when I am off the wall and not really focusing.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>My best friends have ADD-not a big deal.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Meds help-meds make me Normal.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Teen perceptions of AD/HD and taking or not taking medications in inter-dependence mode were that family interaction is positive either staying the same or improving over time and that taking medications helps with family interdependence. Teens that feel different from their families have negative family interaction.

Some teens do not use medications with friends unless they are doing a quiet activity and need to be still and focus. Many teens feel that they do not do anything different in handling AD/HD with their friend with friends. When on medications some teens miss the hyper personality that they enjoy with friends. The sub theme of
interdependence mode is: With meds things are better with my family and friends do not know I am any different.

TABLE 13: How do you Handle AD/HD with Friends?

<table>
<thead>
<tr>
<th>How do you handle this part of your life with your friends?</th>
<th>Do Nothing Different (n=111)</th>
<th>Medication (n=2)</th>
<th>Be active (n=2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do nothing different.</td>
<td>Take my pills and try to control myself and focus- I get fidgety when sitting around.</td>
<td>Try to act crazy when on meds-I feel like I don’t need meds.</td>
<td></td>
</tr>
<tr>
<td>Don’t think about it and it almost goes away.</td>
<td>Take meds and do my normal day.</td>
<td>Talking and playing basketball.</td>
<td></td>
</tr>
<tr>
<td>The more I worry the more obvious it is.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Just handle it-by myself for a long time.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Don’t seem much you have to handle.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nothing different.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Talk and do normal things-doesn’t change at all.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not a big problem-I consider myself a social person.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nothing special.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wouldn’t be different if I didn’t have ADD.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nothing to manage.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Understand that I have AD/HD-but everyone has something different.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>They joke about my test taking but I find it amusing too.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Self-Concept Mode/Group Identity Mode (perceptions of self)

The Self-Concept mode questions focused on cognator coping mechanisms inadequate in perception, learning, judgment, and emotion within the self-concept mode. The sub theme for this section is that Teens with AD/HD feel positive and outgoing about
who they are. The tables and narratives presented in this section illustrate the data used to de-rive the sub theme the role function mode. When asked to describe themselves all the teens were outgoing and positive about who they were. Not one of them faltered about knowing themselves. Their identity did not reflect AD/HD the disorder or the medication. "Just an everyday teenager, pretty much" (Clayton, page 14, line 34).

TABLE 14: Describe Yourself

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Outgoing (n=4)</td>
<td>Talk a lot-like animals and family.</td>
</tr>
<tr>
<td></td>
<td>Fun-creative-impulsive but not overly so.</td>
</tr>
<tr>
<td></td>
<td>Energetic-make people happy when they are sad-help people with problems.</td>
</tr>
<tr>
<td>Authority problem (n=2)</td>
<td>With-rules-I will find a way to break it.</td>
</tr>
<tr>
<td></td>
<td>Why are they considered better than me?</td>
</tr>
<tr>
<td></td>
<td>Not easy to get along with-mostly with adults.</td>
</tr>
<tr>
<td>Can change (n=1)</td>
<td>Completely different person from one week to another.</td>
</tr>
<tr>
<td></td>
<td>It is confusing, changes a lot.</td>
</tr>
<tr>
<td>Good student (n=3)</td>
<td>Hard worker.</td>
</tr>
<tr>
<td></td>
<td>Progressively better student.</td>
</tr>
<tr>
<td></td>
<td>I am actually getting into school-liking physics.</td>
</tr>
<tr>
<td></td>
<td>Try to do things and work hard in school.</td>
</tr>
<tr>
<td></td>
<td>I am in to foreign language.</td>
</tr>
<tr>
<td></td>
<td>All As and Bs in most classes now.</td>
</tr>
<tr>
<td>An everyday teen (n=2)</td>
<td>Doesn’t affect much of what I do.</td>
</tr>
<tr>
<td></td>
<td>An everyday teenager.</td>
</tr>
<tr>
<td>Kind, trusting, giving (n=1)</td>
<td>Kind, trusting, giving.</td>
</tr>
<tr>
<td>Sports/active (n=2)</td>
<td>Like active sports like karate-like hard.</td>
</tr>
<tr>
<td></td>
<td>Work like carpentry.</td>
</tr>
<tr>
<td></td>
<td>Very physical-football, soccer, basketball, baseball.</td>
</tr>
</tbody>
</table>

They appeared to retain who they were with their approach to living life and their focal point identity within their own determination not governed by AD/HD. Many expressed being outgoing and fun. School remains a focal point for 20% of the teens and
requires much of their life energy. The eleven (73%) who were able to answer were very positively about their personality enjoying who they were. "Fun to hang out with, easy to talk to" (Kisses, page 57, line 20). The four (27%) who had no answer were unable to determine the subtle difference between self and personality.

TABLE 15: Describe your Personality

<table>
<thead>
<tr>
<th>How would you describe your personality?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Like people/fun/happy/cheerful (n=10)</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Smart (n=1)</td>
</tr>
<tr>
<td>No answer (n=4)</td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

When asked if having AD/HD affected how you think of yourself three teens (20%) had never thought about that or weren't able to evaluate the concept because they had no reference to not having AD/HD to compare it to. They were just themselves. Seven teens (47%) felt that having AD/HD and taking medications did not affect how they think about themselves. It was interesting that some even felt they took meds for the sake of others. "If it works I'll take it and it's part of my life, so I should use it to help everybody around me. I think it’s a good thing to take medicine for my AD/HD" (Mo, page 65, line 28).
TABLE 16: AD/HD and Medications Affected How you Think of Yourself?

*Has having AD/HD and taking medication affected how you think of yourself?*

<table>
<thead>
<tr>
<th>No (n=7)</th>
<th>Don’t think it has.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>I just think of myself as a normal person with a gift.</td>
</tr>
<tr>
<td></td>
<td>I don’t think of myself as worse or better because of it.</td>
</tr>
<tr>
<td></td>
<td>No-I don’t think all the time ‘I have ADD and that’s bad and I have to take medication.’</td>
</tr>
<tr>
<td></td>
<td>No-without meds works for awhile and I get down-I should use meds to help everyone around me.</td>
</tr>
<tr>
<td>Yes</td>
<td>I am different from a lot of people because I take pills and have more problems.</td>
</tr>
<tr>
<td></td>
<td>I’m unique-something’s not right but with meds, it doesn’t even occur to me.</td>
</tr>
<tr>
<td></td>
<td>I am a better student and that makes me happy.</td>
</tr>
<tr>
<td></td>
<td>At points, I think negatively because I can’t remember things.</td>
</tr>
<tr>
<td></td>
<td>It’s better to know that I am not just a total bomb-there is certain things I have more trouble doing than other people.</td>
</tr>
<tr>
<td>Don’t Know</td>
<td>I don’t know.</td>
</tr>
<tr>
<td></td>
<td>I am never off meds.</td>
</tr>
<tr>
<td></td>
<td>I don’t think about that.</td>
</tr>
</tbody>
</table>

One teen felt that he was unique with a special gift. The remaining five teens (33%) felt strongly that they were different and had difficulties but were able to understand their difference and compensate with medications. The difficulties described were: more problems, something's not right with me, I am a better student with meds, I can't remember things, there are certain things I have more trouble doing.

Teen's perceptions of AD/HD and taking or not taking medications in self-concept/group identity mode are positive feelings of being an every day teenager. Teens with AD/HD feel positive and outgoing about themselves. AD/HD can help or hurt, depending on what you make of it. The sub theme of self-concept/group identity mode is: I'm just an everyday teenager, pretty much.
Wrap Up: Opportunity for the teen to add anything that s/he may want to say about AD/HD and taking medications:

Participants were given an opportunity to add anything they felt was important in the last section of the interview. Teens were then able to speak of feelings independent of formatted questions.

When asked by the investigator if there was anything they wanted to say knowing that this was the wrap up and last chance to make their important feeling known the teens had some significant personal information they wanted to be made known. For the most part the teens felt that if teens "find something (medication) that works for them it is just not a big deal" (Elizabeth, Page 25, line 13). Many teens felt a 'sense of self’ as Name stated, "I think it (AD/HD) doesn't really change the way you look at yourself or the way that other people look at you because you are still the same person. You just need to focus a little better and concentrate a little more" (Name, Page 72, line 14).

One teen wanted to emphatically say the "some people think someone with AD/HD is retarded. We can think perfectly fine." He felt that acceptance of your own AD/HD can help you because you are gifted with more creativity and are more active (Fudo, page 29, line 23). Teens recognize that AD/HD is a disorder that requires medication, just like any other medical problem, for example: acne. One teen felt that ADD was less apparent than AD/HD. One young man wanted everyone know that "AD/HD SUCKS!!" (Kissis, page 57, line 38).
**TABLE 17: What Else Can You Tell Me?**

*What else can you tell me about your experience with having AD/HD and taking medications or not?*

<table>
<thead>
<tr>
<th>Things teens want others to know about ADD or AD/HD.</th>
<th>People think someone with AD/HD is retarded. We can think perfectly fine. You are more active and more creative. You are your own person. It can help or hinder you however, you want to think.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>I am the same as everyone else. Everybody had ADD in some form or at some time. My dog’s ADD!</td>
</tr>
<tr>
<td></td>
<td>AD/HD sucks!!</td>
</tr>
<tr>
<td></td>
<td>AD/HD is a disorder.</td>
</tr>
<tr>
<td></td>
<td>ADD is less apparent than AD/HD.</td>
</tr>
<tr>
<td></td>
<td>ADD doesn’t change the way you look at you because you are the same person. You just have to focus a little better, concentrate.</td>
</tr>
<tr>
<td></td>
<td>I don’t know anything interesting about it.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Regarding Medications</th>
<th>Meds work.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Meds work but make me sick if I take them 3 weeks straight without a break.</td>
</tr>
<tr>
<td></td>
<td>AD/HD is not a big deal with meds. Use meds. People can overcome AD/HD.</td>
</tr>
<tr>
<td></td>
<td>Find the right meds and use them. It’s not smart to not take meds.</td>
</tr>
<tr>
<td></td>
<td>Find meds that work. Go to the doctor. Go to different places for all these tests and try new pills. Whatever works, you have this disease. You can’t get rid of it. You’ve gotta do what you’ve gotta do.</td>
</tr>
<tr>
<td></td>
<td>Meds help.</td>
</tr>
<tr>
<td></td>
<td>All meds affect my appetite except Concerta.</td>
</tr>
<tr>
<td></td>
<td>The longer I wait to take the meds there is more of a difference. It affects concentration, train of thought, ability to start activities, the desire to do work. It really affects your work ethic.</td>
</tr>
<tr>
<td></td>
<td>Compulsive when I am off meds. Eat all the time.</td>
</tr>
<tr>
<td></td>
<td>I lose weight with Adderall.</td>
</tr>
<tr>
<td></td>
<td>Meds make me unable to socialize.</td>
</tr>
<tr>
<td></td>
<td>I look up into space, exclude everything else, and have no clue what’s going on. My mind is a blank. Meds make me able to concentrate.</td>
</tr>
<tr>
<td></td>
<td>Meds won’t calm me down. It’s just a concentrating pill.</td>
</tr>
<tr>
<td></td>
<td>Without meds, some kids go wild and can’t calm down.</td>
</tr>
<tr>
<td></td>
<td>Without meds, some kids get into a lot of trouble.</td>
</tr>
<tr>
<td></td>
<td>After awhile meds don’t give any feeling.</td>
</tr>
<tr>
<td></td>
<td>With meds, I would think twice about dangerous things and not do them.</td>
</tr>
<tr>
<td></td>
<td>I take acne medication for my face and it helps and I take medicine for my AD/HD and it helps.</td>
</tr>
<tr>
<td></td>
<td>My medicine makes me feel better and hopefully other people too.</td>
</tr>
<tr>
<td></td>
<td>Concerta and Metadate make me sick. Ritalin is the best of all.</td>
</tr>
</tbody>
</table>
By far, medications was the subject that most teens wanted to make sure that people know about. They want us to know that meds work and that teens should take their meds. "Find the meds that work. Go to the doctor. Go to different places for all these tests and try new pills. Whatever works, you have this disease. You can't get rid of it. You've gotta do what you've gotta do." (Fudo, page 29, line 43). Some teens had no significant side effects from the medications. Others felt that the meds were worth the side effects of loss of appetite, decreased ability to socialize compared to the hyper mode when off meds, and decreased daring 'Evil Kinevil' bravery, and the sick feeling after taking them for a long time. The meds were worth it because they made the teens able to cope and adapt to self, school, family, friends, and the demands of everyday life. Some teens took meds for their own improved achievements while others took meds for the sake of those around them in increased interpersonal skills like listening, focusing on conversation, and attention to the moment at hand. "Quite often times I forget to take medications and I do notice the difference. And, the longer you wait to start taking it again, the more of a difference you start to see. You notice things like loss of concentration, train of thought, ability to start certain activities, the desire to even do work at all. It really affects your work ethic" (Greg, page 35, line 13-17)

**Theme**

Main theme of Teens’ Perceptions About Attention Deficit Disorder/Attention Deficit Hyperactivity Disorder Medications and Adaptation to Attention Deficit Disorder/Attention Deficit Hyperactivity Disorder is: Meds help me. This main theme is derived from the teen interview sub themes in the four modes of Roy's Adaptation Model.
FIGURE 6: Theme and Sub-Themes in Roy’s Four Effector Behavior Models

Sub-themes

Physiological: "Medications are a hassle but they work."

Role Function: I do better in school when I take the meds.

Interdependence: With meds things are better with my family and friends don't know I am any different.

Self-Concept: I'm just an everyday teenager, pretty much.
CHAPTER FIVE

Discussion of Findings

This chapter presents discussion of the study findings in relation to previously published reports, implications for nursing theory and for school nursing practice, strengths and limitations, and recommendations for future research. This chapter closes with conclusions regarding implications of the study regarding AD/HD medications and teen's perceptions of AD/HD.

Discussion of Findings in Relation to Previous Studies

The purpose of this study was to describe teens’ perceptions about Attention Deficit Disorder/Attention Deficit Hyperactivity Disorder (AD/HD) medications and adaptation to AD/HD including decision-making about taking prescribed AD/HD medications. Results of this investigation will inform school nursing practice with a taxonomy of themes and sub themes of teen perceptions. Roy's Adaptation Model provided an organizing framework for interviewing teens about individual experiences and experiences as part of a group with application to school nursing.

According to Roy, teens must adapt to input. Roy (1993) stated that specific medical problems may arise specific to age groups and consideration must be given to the person’s physiological and psychosocial developmental stage and sense of self/personality. The RAM model and its four modes of physiological/physical, role function, interdependence and self-concept/group identity provided a conceptual model for exploration into teen's perceptions.
AD/HD and the Physiological-Physical Mode (taking or not taking medications)

The physiological-physical mode includes: Five needs—oxygenation, nutrition, elimination, activity and rest, protection four complex processes—senses; fluid, electrolyte, and acid-base balance; neurological function; endocrine function. For AD/HD neurological function is the focus. Previous research suggested that AD/HD has a neurological basis with a positive effect derived from pharmaceutical treatment (USDSS, 1998; Brown, 2000; Biederman, 1998). The newer time released medications require less frequent medication administration. There are deficits in the literature regarding understanding of teen’s own view about their experiences with these medications, how they decide whether or not to take these medications, and what other strategies (other than medications) they may employ to manage their situations (Efron, et al, 1998). This study contributes valuable knowledge of the teen’s own perspective regarding effects of medications and treatments as experienced by the individual with AD/HD.

Most of the sample felt that AD/HD medications are beneficial for the symptoms of AD/HD and want people to know that 'meds work!' and 'teens should take their meds!' Teens found medications too beneficial to stop taking even with the perceived 'hassle' of taking medications, the effects of anorexia, or the decreased social skills lost due to the calming effect. Teens feel the 'hassle' of remembering to take AD/HD medication was lessened by taking the newer time released medications once a day.

The National Institutes of Mental Health Booklet describing AD/HD (2003) states that stimulants do not make the child feel high, although some children say they feel different or funny (NIMH, 2003). Many teens in this study expressed that they didn't feel
any different when on medications and believed the benefits only when looking back at
evidence of better grades, improved teacher: student relations, and observations of friends
regarding changed behavior. These teens were at an age and developmental stage where
they have lived with AD/HD and found coping mechanisms that work and used them.
Teens expressed that it requires persistence to 'do what you've gotta do' to find the right
medication and take the medication. Medications made these teens feel equal and the
same as anyone else.

AD/HD and the Role Function Mode (student)

Roy’s role function mode addresses the need for psychic and spiritual integrity so
that one can be or exist with a sense of unity, meaning, and purposefulness in the
found that children with AD/HD have difficulty retrieving and using information and
Selekman and Snyder (1996) write that inattention problems can seriously interfere with
school role performance and often accompany academic skills disorders. Frame (2003)
determined that perceptions can be defined and measured using Harter's Developmental
Perspective. This study allowed teens to express perceptions freely in response to open
ended questions. The teens responded to the open ended questions with candid personal
perceptions about themselves and AD/HD.

Good study skill habits like organizing, planning, or developing focusing skills all
help but medications seem to make the difference. Most teens feel they can perform at
higher adaptive levels of increased concentration/focus, attention, listening, memory, and
control in their role function at school with medications. All teens in this study had been
off medication at one time or another and the decline in school performance confirmed this perception. These teens appear to work through 's Learning Identity vs. Identity Diffusion (Fidelity) with perceptions of being 'the same as everyone else' when taking medication.

**AD/HD and the Interdependence Mode (family and friends)**

Roy’s Interdependence mode addresses the need to achieve relational integrity using the process of affectional adequacy, i.e., the giving and receiving of love, respect, and value through effective relations and communication. Social acceptance is a key life skill necessary for teens in developing relationships with friends and family. Impulsivity, lack of control, and inattention do not foster interdependence. I must support Hoza's 1993 findings that found that boys with AD/HD viewed themselves with self perceived confidence. The teens in this study also had self perceived confidence. These teens feel that they act no differently with friends than any other teenager and that interactions with family and friends are positive. With medications teens perceive that friends don't know they are any different.

Kendall's (2003) study of 39 children and adolescents found themes that are dissimilar to the findings of this study. She found the children unable to separate themselves from their AD/HD, that they were 'parroting back' negative descriptions they had heard about themselves, or that they were mad, frustrated, sad or ashamed. Kendall's study found that children felt medications helped the most of all the treatments. My study confirms that perception in teens. However, my study group of teens did not feel fear or shame from taking medications as was found in Kendall's group. Unlike Kendall's study,
this study found that most teens felt positive about themselves, their families, and their friends when taking medications.

**AD/HD and the Self-Concept/Group Identity Mode (perceptions of self)**

Roy’s Self-concept/group identity mode includes the composite of beliefs and feelings that one holds about oneself at a given time, formed from internal perceptions and perceptions of other’s reactions, and directing one’s behavior. Dumas and Pelletier (1999) found that self-perceptions were lower among children with AD/HD. Krueger and Kendall (2001) concluded that teens with AD/HD had a distorted perception of self, unable to separate their definition of self from the disorder.

This study found most teens to feel positive about themselves as outgoing, a good student, an everyday teen, and in sports/active. Most teens felt they knew their differences and compensated with medications and that having AD/HD and taking medications has not affected how most teens think of themselves.

**Implications for School Nursing Practice**

With almost 4 million youth diagnosed with AD/HD, this is indeed an area of concern appropriately within the needs based assessment and intervention of school nursing. This study informs school nursing of teen's perceptions about AD/HD useful in nursing interventions for increased adaptive outcomes. School nurse interventions help teens and families adapt with the physical, mental, behavioral, and social aspects of this condition.

The teens in this study perceived AD/HD symptoms of diminished concentration/focus, inattention, difficulty listening, distractibility, fidgeting, and
forgetfulness as stressing their role function at school and their interdependence with friends and family at home. Teens that respond to and find the right medications have hoped to minimize the symptomatic burdens of AD/HD. As one teen said, “People can overcome AD/HD. Find the meds that work. Go to the doctor and to different places for all these tests and try new pills. Whatever works, you have this disease. You can't get rid of it. You've gotta do what you've gotta do.”

Teens with AD/HD can work through Erikson's review of the adolescent’s sense of trust, autonomy, initiative, and industry in Learning Identity vs. Identity Diffusion (Fidelity) with fewer deficiencies if the right medication and dose can be found. High School Nurses are a vital link for professional collaboration between healthcare providers, schools, educators, and families to promote teen adaptation to AD/HD.

**Strengths and Limitations**

The real strength of this study was that it was met with little reluctance by the teens as they eagerly presented their own new and original adolescent thought processes about AD/HD and most especially regarding the newer medications. This investigator found teens and teen's families to be supportive and encouraging to this study. The open ended questions were well received and presented a springboard for original thought and response. The question format worked well for response in brevity and for the verbose teen. The resulting data were candid and contemplated.

The sample is strengthened with the gender male: female (10:5) ratio similar to what is found in the population of children with AD/HD. Sample strength also includes the valuable new data exclusively derived from teens actively taking advantage of
medication therapy with sixty seven percent of the teens in this study taking the new time released medications.

The foundational strength of the study was the applicability of the Roy Adaptation model to order these data in meaningful representations of the teens' perceptions. The worldview of Roy's four modes illuminates the wealth of knowledge these teens' perceptions reveal by recognizing the stimuli of AD/HD to the body and mind that produces adaptive or ineffective internal or external behavior. Viewing these perceptions through physiologic/physical, role function, interdependence, and self concept/group identity behavioral effector modes give meaning to these data.

One limitation of the study is transferability of the data. These data can't be generalized to the population that doesn't take medications or doesn't have access to healthcare. This teen sample was from a high school in an upper socioeconomic status area with single family dwellings and family support (with the exception of one father that did not support taking medications). These teens had access to healthcare throughout their lives and explored many medications. Conversely, for the purposes of exploring the positive effects of medications experienced by teens with consistent healthcare interventions, this is a strength of the study.

Another limitation of this study was that interviews were set up after school at a time when medications have worn off and the ability to focus and concentrate may have been impaired. Some teens experienced wandering thoughts and inability to articulate an answer to the questions with clarity and purpose. Although completely cooperative, some had difficulty focusing and didn't seem to realize that they had difficulty focusing.
Recommendations for Future Study

There is a major deficit in existing studies regarding teen's perceptions about AD/HD and AD/HD medications. This study could be replicated with a larger and more diverse sample including several different schools with varied socioeconomic groups for more generalizable data.

Roy's Adaptation Model would be useful in diverse sample studies. The concepts are valuable to nursing practice interventions. This paradigmic perspective can draw a picture with the interrelated relationships of physiological/physical, role function, interdependence, and self concept-group identity behavioral effector modes.

As the most diagnosed mental illness in children, AD/HD warrants a longitudinal study of success stories with medications. This study found many teens that have positive attitudes with a winning combination of cutting edge healthcare and family support. This adds evidence of variability at the positive end of teens with AD/HD medications.

Future studies should consider interviewing in the morning while medications are therapeutically functional for optimal attention to the questions. Study could be done with teens not taking medications. More knowledge is needed regarding perceptions of teens diagnosed with AD/HD and choosing not to be on medications.

Conclusions

School nurses can use the knowledge gained from this study in collaborative work with teens with AD/HD, their families, healthcare providers, schools, teachers, and communities to benefit teens. Knowledge of teen's perceptions about AD/HD medications, including the new time released medications, is that medications definitely
improve: attention deficits, school performance, learning, coping, and controlled
activities socially and at school. Students with AD/HD are “everyday teenagers, pretty
much,” and that AD/HD can be “no big deal” with medications. “If they have the right
medicine and they take it every day” (Elizabeth, page 25, line 12). In conclusion, school
nurses can approach teens knowing that teens with AD/HD feel: “You are your own
person” and that “Meds help.”
APPENDIX A

CONSENT FORM
CONSENT FORM

Teens Perceptions About AD/HD Medications and Adaptation to AD/HD

I AM BEING ASKED TO READ THE FOLLOWING MATERIAL TO ENSURE THAT I AM INFORMED OF THE NATURE OF THIS RESEARCH STUDY AND OF HOW I WILL PARTICIPATE IN IT, IF I CONSENT TO DO SO. SIGNING THIS FORM WILL INDICATE THAT I HAVE BEEN SO INFORMED AND THAT I GIVE MY CONSENT TO PARTICIPATE. FEDERAL REGULATIONS REQUIRE WRITTEN INFORMED CONSENT PRIOR TO PARTICIPATION IN THIS RESEARCH STUDY SO THAT I CAN KNOW THE NATURE AND RISKS OF MY PARTICIPATION AND CAN DECIDE TO PARTICIPATE OR NOT PARTICIPATE IN A FREE AND INFORMED MANNER.

PURPOSE
I am being invited to consent to participate voluntarily in the above-titled research project. The purpose of this project is to develop a knowledge base about teens and their perceptions about their meds and their AD/HD.

SELECTION CRITERIA
I am being invited to consent to participate because I attend CDO, I am currently taking medications for AD/HD, and I am 14-17 years old.

Approximately 10-16 teens will be enrolled in this study. My care at CDO in the school nurse office will not be affected in any way by my decision to participate or not to participate in the study. In addition, other staff at CDO will not know who participates in the study.

PROCEDURE(S):
If I agree to participate, I will be asked to consent to the following:

Ms. Knipp will help me understand the study and if I want to I will voluntarily give my consent to be in the study. At that time I will be asked to fill out the demographics form of gender, age, medications, duration of medications.

If I agree, then Ms. Knipp will arrange for a personal interview immediately or by appointment after school in the school nurse office or at home at a time when a guardian can be home. The interview will be conducted in a location that affords privacy. The interviews are expected to last 1-2 hours, and will be audiotape-recorded for later conversion to written words, with an anonymous name chosen by me.

Interviews will begin by asking me to describe experiences about when I was first diagnosed with AD/HD, and will progress through “stories” to the present time, and future plans. I will be guided to explain experiences with medications, (side effects and benefits), how I currently manage the situation. I will tell what helps and what doesn’t help in managing AD/HD. Questions during the PI/teen interview will be open ended questions allowing me to speak freely. Of course, at any time, I can stop the interview.
with no hard feelings. This is to gather anonymous information and not in any way meant to cause any problems.
I agree that I may one of the teens invited to participate in follow-up interviews to ask whether I agree with the results of the study.

RISKS
There are no significant risks involved with this study. However, if I experience emotional discomfort from describing experiences with AD/HD counseling with school counselors and with my healthcare provider is recommended.

BENEFITS
There are no direct benefits to me to participate in this study. The proposed study is designed to elicit my perceptions about managing AD/HD, including decision-making about prescribed medications. Results of this study will help form recommendations for school nursing practice to enhance positive health outcomes for high school students with ADD or AD/HD. Results from this study may also be useful to other professionals involved with students with AD/HD such as teachers, healthcare providers as well as parents and teens themselves. Without an understanding of the teen’s views about health care, school nurses and other health care providers may “miss the mark.” Ineffective health care may result in long-term, negative health outcomes for teens.

CONFIDENTIALITY
Names will not appear on any of the research documents. No one at CDO other than the researcher will know I am in this study. I will choose an anonymous name that we will call me for the purposes of this study. At no time will my real name be linked to the data.

PARTICIPATION COSTS AND SUBJECT COMPENSATION
There are no known costs to me to participate in this study except 1-2 hours of time for the interview and then a possible 2nd interview. As a thank you for my time for the interview I will receive a $15.00 gift certificate to Barnes and Noble Bookstore (the approximate cost of a book or CD).

CONTACTS: I can obtain further information from Ms. Knipp at (520) 696-5576. If I have questions concerning my rights as a research subject, I may call the University of Arizona Human Subjects Committee office at (520) 626-6721.

AUTHORIZATION: BEFORE GIVING MY CONSENT BY SIGNING THIS FORM, THE METHODS, INCONVENIENCES, RISKS, AND BENEFITS HAVE BEEN EXPLAINED TO ME AND MY QUESTIONS HAVE BEEN ANSWERED. I MAY ASK QUESTIONS AT ANY TIME AND I AM FREE TO WITHDRAW FROM THE PROJECT AT ANY TIME WITHOUT CAUSING BAD FEELINGS. MY PARTICIPATION IN THIS PROJECT MAY BE ENDED BY THE INVESTIGATOR FOR REASONS THAT WOULD BE EXPLAINED. NEW INFORMATION DEVELOPED DURING THE COURSE OF THIS STUDY WHICH MAY AFFECT
MY WILLINGNESS TO CONTINUE IN THIS RESEARCH PROJECT WILL BE GIVEN TO ME AS IT BECOMES AVAILABLE. THIS CONSENT FORM WILL BE FILED IN AN AREA DESIGNATED BY THE HUMAN SUBJECTS COMMITTEE WITH ACCESS RESTRICTED TO THE PRINCIPAL INVESTIGATOR, Diana Kathleen Knipp, OR AUTHORIZED REPRESENTATIVE OF THE COLLEGE OF NURSING DEPARTMENT. I DO NOT GIVE UP ANY OF MY LEGAL RIGHTS BY SIGNING THIS FORM. A COPY OF THIS SIGNED CONSENT FORM WILL BE GIVEN TO ME.

Subject’s Signature ___________________________ Date __________

Parent/Legal Guardian ___________________________ Date __________

INVESTIGATOR'S AFFIDAVIT
I have carefully explained to the subject the nature of the above project. I hereby certify that to the best of my knowledge the person who is signing this consent form understands clearly the nature, demands, benefits, and risks involved in his/her participation and his/her signature is legally valid. A medical problem or language or educational barrier has not precluded this understanding.

Signature of Investigator, Ms. Knipp ___________________________ Date __________
APPENDIX B

PHONE SCRIPT FOR PHONE FOLLOW-UP OF PARENT LETTER
Hello, I am Kathy Knipp, and I am calling to find out if you received the letter inviting you and (teen’s name) to participate in my Research study about kids with AD/HD? It is an important study trying to understand what the kids are thinking about their AD/HD and their medications. I am trying to learn what the kids are thinking. I just want you to know that whether you decide yes or no to this research it will not affect (teen’s name) school nurse experience. Yes is good and no is good. What ever is convenient for you and (teen’s name).

Did you have any questions or concerns about the study that I can help you with?

Would you be willing for me to meet with (teen’s name) for an interview?

(Parent responds “yes”)

Thank you so much. I will need your signed consent. I would like to get permission from (teen’s name). Can you recommend a good time to contact (teen’s name) for consent and an interview?

(Parent responds “no”)

Your “no” to this research is fine with me. Thank you so much for allowing me to speak with you. We will have a great school year and I will enjoy seeing (teen’s name) sometime at CDO.

Thank you, Goodbye
APPENDIX C

PARENT COVER LETTER
The University of Arizona College of Nursing

Title: Teens Perceptions About AD/HD Medications and Adaptation to AD/HD

Researcher: Diana Kathleen “Kathy” Knipp, Graduate Student

Dear (Parents Name Inserted),

You are being asked for your teen to voluntarily participate in a study about Teen’s ideas and feelings about their meds and how they cope with AD/HD.

Purpose: The purpose of this study is to develop a knowledge base about teens and their perceptions about their meds and their AD/HD.

What’s involved? If you decide to be in the study, your teen will commit to 1-2 interviews with Nurse Kathy for 1-2 hours. Your teen will be asked to talk about experiences with medications and AD/HD. Your decision about this study will not in any way affect healthcare in the CDO nurse office. Yes or No will be appreciated and will not affect your CDO experience.

Confidentiality: Your names will not appear on any of the research documents. No one at CDO will know your teen is in this study. Your teen will chose a fake name that we will call your teen for the purposes of the study. At no time will the real name be documented.

Risks: There are no known risks involved for you and your teen’s participation in this study. If at any time information comes forth that indicates any self harm or harm to others the interview will end and the parents will be notified.

Questions: You and your teen can ask questions at any time during the study, and I will answer questions. In addition, your teen can decide not to answer any of the questions in the study.

Withdrawal: You and your teen can change your mind about being in the study at any time, and there will be no hard feelings.
APPENDIX D

INTERVIEW QUESTIONS
INTERVIEW QUESTIONS
(organized by pre-set categories (consistent with content analysis).

Data Collection Protocol:

Preliminary to the Interview:
Obtain Consent
Decide on a pseudonym

Interview guide: (Organized using Roy’s Four Modes of Adaptation (Physiological, Role Function, Interdependence, and Self-concept/group identity):

I. Tell me about your experience with being diagnosed with ADD or AD/HD.
   Prompts: “How old were you”? What was going on at that time? What did you think and feel about it all?

II. Physiological Mode: (Taking/ not-taking medications)
   a. When you first started taking medication, how did you feel?
   b. Do you remember what medications you took?
   c. How did it feel to take the medications?
   d. What is it like now?

III. Role function Mode: (experience as a student)
   a. What has it been like for you at school?
   b. What effect do you think taking medications has had on your school work.
   c. What else do you do to manage your school experiences?

IV. Interdependence Mode: (family & friends)
   a. What is it like for you with your family regarding having AD/HD & taking medications?
   b. Has this changed over time, as you got older?
   c. What has it been like for you with your friends, with having AD/HD & taking medications?
   d. How do you handle this part of your life with your friends?

V. Self-Concept Mode (Perceptions of self)
   a. How would you describe yourself? Your personality?
   b. Has having AD/HD and taking medication affected how you think of yourself?

VI. Wrap – up: Opportunity for teen to add anything that s/he may want to say.
   What else can you tell me about your experience with having AD/HD, and taking medications or not?
APPENDIX E

DEMOGRAPHIC DATA FORM
DEMOGRAPHICS FORM

Gender: M ____ F ____

Age: _____ years

Grade: _____

Diagnosis (I, HI, or C) _____ (SEE CHART BELOW)

<table>
<thead>
<tr>
<th>Predominately inattentive type: (AD/HD-I)</th>
<th>Predominately hyperactive-impulsive type: (AD/HD-HI)</th>
<th>Combined type: (AD/HD-C)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Who made the diagnosis (pediatrician, psychiatrist, psychologist, other?)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Age of 1st diagnosis _____ years

<table>
<thead>
<tr>
<th>Present Medications For AD/HD</th>
<th>Dose</th>
<th>How long on this medication?</th>
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</tbody>
</table>

Other Diagnoses? 

_______________________ meds ________________

_______________________ meds ________________

_______________________ meds ________________
APPENDIX F

LETTER OF APPROVAL -

AMPHITHEATER PUBLIC SCHOOLS
January 22, 2004

Ms. Kathy Knipp
Canyon del Oro High School

Dear Ms. Knipp:

The Amphitheater District Research Committee has completed a review of your research proposal. Your request to conduct research at Canyon del Oro High School has been approved.

Please contact Mr. Gemma before proceeding. If you have any questions, feel free to contact me at 696-5172.

Sincerely,

Patrick Nelson
Associate Superintendent

cc: Mike Gemma
REFERENCES


Friedman, M., Bowden, V., Jones, E., (2003). Family nursing: research, theory, and practice (5\textsuperscript{th} ed.). Upper Saddle River: Prentice Hall.


