

ABSTRACT

THE PROCESS OF SEEKING TREATMENT: HOW FAMILIES ACCESS CARE FOR CHILDREN WITH ADHD

By Ryan J. Hermus

Attention deficit hyperactivity disorder (ADHD) is one of the most common mental health diagnoses in children and adolescents. According to the Centers for Disease Control, Summary Health Statistics for U.S. Children (Bloom & Cohen, 2007), 4.5 million children in the United States have ADHD. Attention deficit hyperactivity disorder is a chronic condition that can significantly impact academic performance, social interaction, self-esteem, and family function. Abundant research exists regarding treatment modalities, pharmacotherapy options, effectiveness of different treatment modalities, and family perceptions and attitudes towards ADHD treatment. Little is known about the experiences and processes families undergo when seeking treatment for their children who display signs and symptoms of ADHD.

The purpose of this study was to explore the process by which families seek treatment for their children with ADHD. Glazer and Strauss' (1967) Grounded Theory was utilized as the theoretical framework for this study.

This was an inductive qualitative design utilizing naturalistic inquiry. A convenience sample of seven parents from a Midwestern outpatient child and adolescent mental health clinic was recruited by mail. One interview was conducted as a pilot interview and was not included in data analysis. Data collection included demographic questionnaires and unstructured interviews, using open-ended questions to elicit information related to the process of seeking treatment for families of children with ADHD. Data were analyzed using descriptive statistics and Collaizi's (1978) method of qualitative analysis noting recurring themes. An overarching theme, four major themes, and multiple subthemes were identified. The overarching theme was *Journeying to Make Meaning of ADHD*. Major themes included *Getting Started*, *Gathering Information*, *Understanding*, and *Following Things Through*.

The significance of the topic to primary care is related to the ability for providers to better understand how families seek treatment for their children so that proper community resources, education, and interventions may be presented to families and their children in a timely manner.

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FOR CHILDREN WITH ADHD

by

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I dedicate this paper to my wife Lisa and daughter Ella.

Lisa, without your love, understanding, and patience I would never have realized my full potential as a student, a nurse, and a husband.

Ella, for all the times you asked Daddy to play with you and I couldn't; I promise to make up for those moments many times over.

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Chapter I

Introduction

Attention deficit hyperactivity disorder (ADHD) is one of the most frequently diagnosed medical conditions in children and adolescents in the United States, with a prevalence of 4% to 8% (Goodman, 2010; Kendall, Leo, Perrin, & Hatton, 2005; Salmeron, 2009). Children with ADHD display behaviors of inattention, impulsivity, and hyperactivity (Faraone, 2005; Goodman, 2010; Salmeron, 2009). These children also experience more difficulty with social and peer interactions, academic performance, and self-esteem (Carpenter-Song, 2009; Salmeron, 2009). Families who have children with ADHD experience more emotional and social difficulties compared to families who do not have a child diagnosed with ADHD (Bussing, Koro-Ljungberg, Williamson, Gary & Garvan, 2006; Salmeron, 2009). Many families with children who have ADHD do not seek professional treatment for their child (Cunningham, 2007; Kendall et al., 2005). The majority of families who seek treatment for their child choose pharmacotherapy and behavioral modification (Faraone, 2005; McLeod, Fettes, Jensen, Pescosolido, & Martin, 2007). Treatment strategies for children with ADHD include pharmacotherapy, individual and family counseling, behavior modification, diet modification, and self-care by parents/guardians (Bussing et al., 2006; Johnston, Siepp, Hommersen, Hoza, & Fine, 2005; McLeod et al., 2007; VanCleave & Leslie, 2008).

Many studies have been conducted related to the pharmacological treatment of ADHD in children and adolescents (Dopheide, 2009; Engler, N., 2008; Faraone, 2005; Goodman, 2010; Miller-Horn et al., 2008; Poncin, Sukhodolsky, McGuire & Scahill, 2007; VanCleave & Leslie, 2008). Other studies researched the effectiveness of different

treatment modalities for ADHD (Carpenter-Song, 2009; Corkum, Rimer, & Schachar, 2005; Cunningham, 2007; Evans, Schultz, & Sadler, 2008; Johnston et al., 2005; McLeod et al., 2007). Few studies (Kendall, 2007; McLeod et al. 2007) have investigated the experiences of families with children who have ADHD. McLeod et al. (2007) conducted a combined qualitative and quantitative study related to public knowledge, beliefs, and treatment preferences concerning ADHD. The majority of parents surveyed believed ADHD was a real medical condition and endorsed medication and therapy as effective treatment modalities for ADHD; less than half of those surveyed sought formal treatment. The authors did not investigate the reason those who did not seek treatment chose not to do so or the process and reasons for families seeking or not seeking treatment.

Bussing et al. (2006) conducted a combined qualitative inquiry and quantitative analysis of parental self-care modalities in families with children who displayed symptoms of ADHD or had been formally diagnosed with ADHD. Family ethnicity and socioeconomic status were significant factors predicting whether families sought formal treatment or practiced self-care for their children. Bussing et al. did not investigate how families came to know their child had symptoms of ADHD, or how families gained knowledge about treatment or the process by which families sought treatment.

Carpenter-Song (2009) conducted a 13-month ethnographic study investigating the meanings and experiences of families who had children diagnosed with ADHD, bipolar disorder, and other mental illness. The author described the experience of living with a child diagnosed with ADHD and the day-to-day struggles that family experiences. However, Carpenter-Song did not describe how families sought treatment for their children or when they first noticed their child might have had symptoms of ADHD.

Johnston et al. (2005) explored parents' experiences with different treatment modalities for their children with ADHD. The majority of families in the study chose behavioral management and medications for their children. Half of the families surveyed used vitamin/diet therapies. The process by which families sought the treatment modalities was not discussed in the study.

Although these studies explored patient and family perceptions, attitudes, and experiences with treatment modalities for their children with ADHD, none of the studies or other literature explored the process by which families seek treatment for their children with ADHD. The intent of this study was to investigate the process to better understand how families seek treatment for their children.

Significance of the Problem for Advanced Nursing Practice

Attention deficit hyperactivity disorder is a common chronic medical condition affecting both children and their families. Family nurse practitioners (FNPs) play a critical role in evaluating and diagnosing conditions and diseases in children and adults and providing holistic care to patients and families. Many families first present to their primary care providers when their children display signs and symptoms of ADHD (Kendall et al., 2005; Miller, Johnston, Klassen, Fine, & Papsdorf, 2005; Salmeron, 2009). Family nurse practitioners have the resources and ability to screen, evaluate, diagnose, treat, refer, and collaborate with other professionals (teachers, mental health professionals) to provide individualized care for families and children with ADHD (Bussing et al., 2006; Johnston et al., 2005). An understanding of the process by which families seek treatment for children with ADHD will allow the advanced practice nurse to

better utilize available resources and assist children and families with earlier diagnosis and treatment of ADHD.

Problem Statement

Research abounds regarding medication efficacy and options (Bloom & Cohen, 2007; Dopheide, 2009; Engler, 2008; Goodman, 2010; Johnston et al., 2005; Miller-Horn et al., 2008), treatment modalities (Bloom, 2007; Corkum et al., 2005; Engler, 2008; Goodman, 2010; Johnston et al., 2005; McLeod et al., 2007; Salmeron, 2009), and family perceptions and beliefs about ADHD (Bussing et al., 2006; Carpenter-Song, 2009; Corkum et al., 2005; Cunningham, 2007; Kendall, 2007; McLeod et al., 2007). Research also exists regarding the economic impact of childhood ADHD on healthcare systems (Engler, 2008; Salmeron, 2009), and provider perceptions, abilities, and comfort treating children and families with ADHD (Engler, 2008; Ghanizadeh, 2007; Goodman, 2010; Miller et al., 2005; Miller-Horn et al., 2008; Poncin et al., 2007; Salmeron, 2009, VanCleave & Leslie, 2008). There is currently a gap in literature that explores the experiences of families seeking care or how families seek care for children and adolescents with ADHD.

Purpose of the Study

The purpose of this study was to explore the process of how families seek treatment for children with ADHD. The researcher's intent was to better understand the course families take to seek treatment for children with ADHD.

Research Question

What is the process by which families seek treatment for children with attention deficit hyperactivity disorder (ADHD)?

Definitions

Conceptual definitions.

Process: A method of action; a series of steps or events that lead to achievement of specific results (Venes, 2005, p. 1893).

Family: A group of people living in a household who share common attachments, such as mutual caring, emotional bonds, regular interactions, and common goals, which include the health of the individuals in the family (Venes, 2005, p. 846).

Seek: To go in search of, look for. To try to discover (in Meriam-Webster, 2010).

Treatment: Medical, surgical, dental, or psychiatric management of a patient. Any specific procedure used for the cure or the amelioration of a disease or pathological condition (Venes, 2005, p. 2366).

ADHD: A group of symptoms including impulsivity, hyperactivity, inattention, mood swings that is persistent and more severe than typically observed in children of similar developmental levels (Carpenter-Song, 2009; Goodman, 2010; Kendall et al., 2005).

Operational definitions.

Process: A specific set of actions or steps in seeking treatment for ADHD with the intent of achieving a goal as reported by parent participants.

Family: In this study, whatever the family defines itself as, and must include a legal guardian or at least one parent of the child with ADHD, and at least one child with ADHD.

Seek: To look for or try to obtain as reported by the parent/guardian.

Treatment: Any of the following methods employed or recommended by a health care provider (primary care physician, pediatrician, nurse practitioner, psychiatrist, therapist, psychologist, or counselor) meant to alleviate or lessen the child's symptoms: Pharmacotherapy, cognitive behavioral therapy, behavioral modification, interventions or evaluation in the academic setting, or dietary modification/vitamins (Bussing et al., 2006; Corkum et al., 2005; Goodman, 2010; Johnston et al., 2006; McLeod et al., 2007) as reported by parent participants.

ADHD: Medical diagnosis of ADHD using the following ICD-9 codes: 314.00, 314.01, and 314.9 according to DSM-IV TR (2005) criteria.

Assumptions

The following assumptions were made in this study:

1. Families seek treatment for children with ADHD.
2. All families follow a process to seek treatment for their children with ADHD.
3. Parents and/or guardians will be able to accurately and honestly describe their process of seeking treatment.
4. ADHD is a clinically diagnosable medical condition.

Chapter Summary

In this chapter, the background of the study, significance to advanced nursing practice, problem statement, research question, definition of terms and assumptions were explained and defined. Currently little is known about the process by which families seek treatment for their children with ADHD. This study can provide healthcare professionals with a better understanding of this process to allow provision of timely and accurate education, treatment options, and information about childhood ADHD to families.

Chapter II

Theoretical Framework and Review of Literature

The purpose of this study was to explore the process by which families seek treatment for children with ADHD. Glaser and Strauss' (1967) grounded theory (GT) was used as the theoretical framework to guide this study. The review of literature was categorized into three themes: ADHD as a medical diagnosis, treatment of ADHD in children and adolescents, and ADHD and family experiences and perceptions.

Theoretical Framework

Glaser and Strauss' GT (1967) guided the inquiry into the process of how families seek treatment for their children with ADHD. Grounded theory is a systematic methodology of inductive qualitative inquiry. Grounded theory is rooted in symbolic interactionism and it includes the belief that meaning is constructed and changed by interactions among people. The emphasis of GT encompasses constant comparison of data to describe social phenomena (Glaser & Strauss, 1967). The overall goal of GT is to develop theory from data gathered in the field, more specifically theory developed from the exploration of social process present within human interactions. Theory is developed from both inductive and deductive methods with theory emerging from specific observations and data (Speziale & Carpenter, 2007). Grounded theory is best applied when the researcher decides there is an observed social process requiring description and explanation. For this study, the researcher explored the social process of families seeking treatment with children who have ADHD, then systematically described and explained this process.

Grounded theory is an inductive and deductive methodology used to generate theory out of qualitative data with the philosophical goal of developing theory about social processes rather than to describe a particular phenomenon (Speziale & Carpenter, 2007). Grounded theory assumes that each group under study shares a specific social problem that is not easily articulated. Theory generated from the data is categorized as either formal or substantive theory through the use of comparative analysis. In comparative analysis, groups or subgroups of people are compared for similarities and differences. Exploration of data leads to patterns of behavior leading to general concepts. Concepts are then built into theoretical propositions. Depending on the area of inquiry and the overall goal of the research involved, either substantive or formal theory is deemed appropriate for a particular process of interest. Glazer and Strauss (1967) define substantive theory as middle range theory designed for empirical inquiry (for example a specific area of inquiry, i.e. seeking treatment or getting help); whereas, formal theory is middle range theory developed for conceptual areas of inquiry (for example inquiry into socialization or behavior). The development of a substantive theory was most appropriate for this researcher's inquiry, as the topic of interest was an empirical inquiry to explore the process by which families seek treatment for children with ADHD. A diagram of the key components of grounded theory follows.

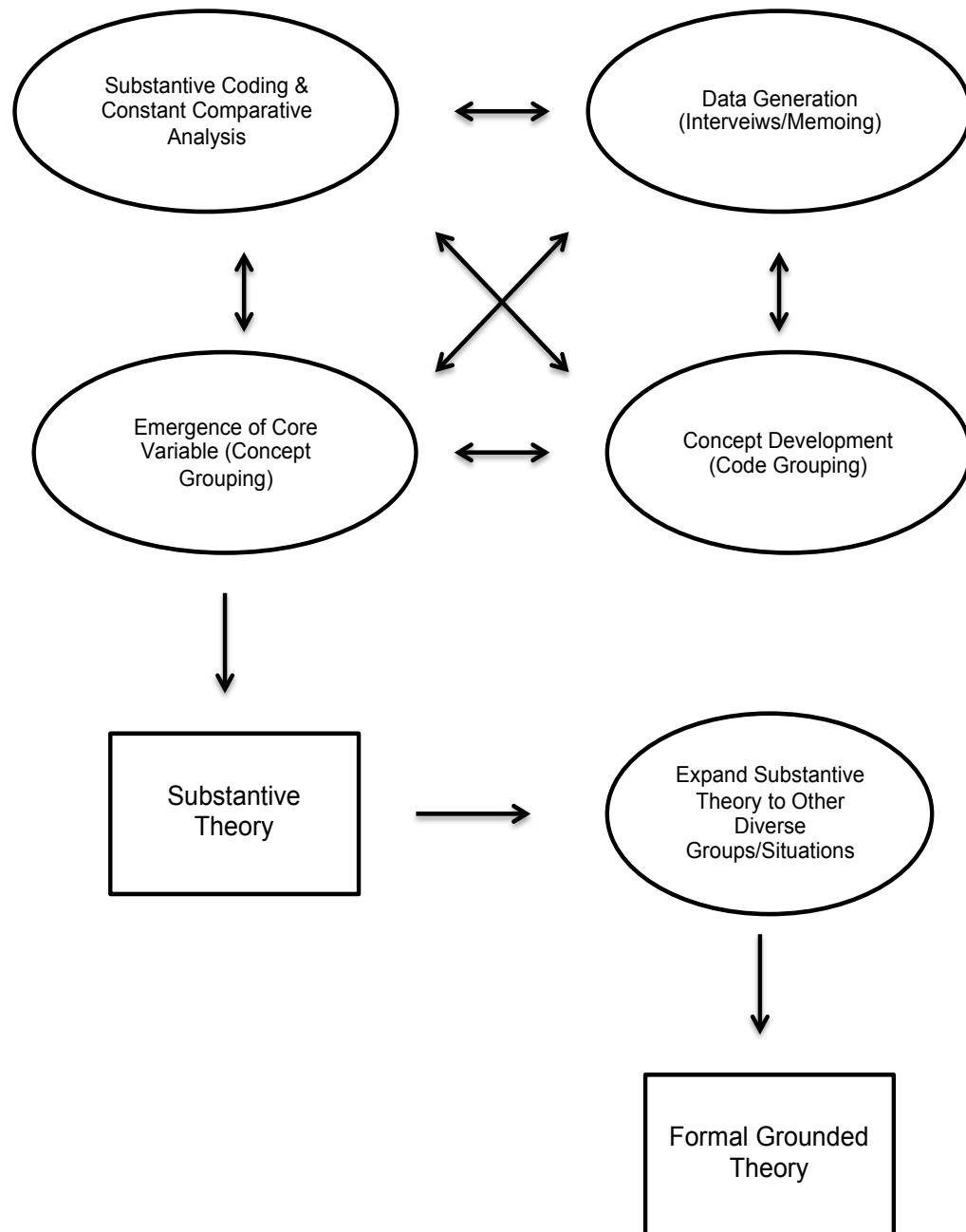


Figure 1: Glazer and Strauss' (1967) Grounded Theory Method

Case Study

A case study using grounded theory follows. A nursing researcher desired to understand the process of transitioning from a registered nurse to becoming an advanced practice nurse. The researcher conducted a literature review to identify current gaps in knowledge on the subject. The researcher recruited parent participants and collected data through personal interviews and questionnaires. Interviews were transcribed and the researcher coded each interview line by line to extract meaning and detail about the process. The researcher compared codes between interviews, developed categories based on the coded data using constant comparison to uncover similarities and differences in the categories discovered through coding the raw data and comparing across interviews. Theoretical sampling was used to obtain data from nurses who were in different stages of the process. Data were categorized and compared to categories already discovered to validate categories and add to the categories. The researcher used memoing to note similarities and differences in the categories, developing themes from the data and presenting the process of transition based on themes and subthemes extracted from memoing, coding, and categorizing the data. All categories, themes, and subthemes were supported by raw data using quotations extracted from the interviews that supported the categories and themes discovered by the researcher. During the data collection process existing themes were analyzed and compared to emerging data through the process of constant comparison. A core variable was identified through analysis of themes and subthemes. The core variable described the overall process of transition to advanced practice, and this core variable became the substantive theory of the process of transitioning to advanced practice. The

researcher presented the process through table or figure format to conceptualize the process under study.

Grounded theory was used as the theoretical framework because the process by which families seek treatment for children with ADHD had not been identified at the time this research was conducted. Data already existed related to the research was scant and not well understood.

Review of Literature

Following is a review of pertinent literature regarding children, families, and ADHD. The review is presented in three sections: ADHD as a medical diagnosis, treatment of ADHD in children and adolescents, and ADHD and family experiences and perceptions.

ADHD as a medical diagnosis.

Attention deficit/hyperactivity disorder is one of the most common childhood psychiatric disorders in the United States, affecting between 7% and 8% of all children and adolescents age 3 to 17 years (Faraone, 2005; Goodman, 2010; Salmeron, 2005). Faraone (2005) conducted a systematic review of studies supporting the scientific foundation of ADHD as a valid psychiatric disorder in children. According to Faraone 87% of all practitioners accept ADHD as a valid medical diagnosis, and 76% of the same population of practitioners indicated that stimulants are over-prescribed and unnecessary, leading to uncertainty and lack of comfort with parents about medicating their children. Faraone summarized quantitative experimental studies that used valid screening tools for ADHD and reported the tools were valid tools, with Cronbach's alpha between 0.77 and 0.89. This systematic review is relevant to families seeking treatment

for children with ADHD. Faraone recommended that primary care providers screen children and adolescents for ADHD, ask family history questions about the signs and symptoms of ADHD, and provide accurate information about treatment options for families.

Salmeron (2005) conducted a systematic review related to the diagnosis of ADHD, effects of ADHD on the family unit, and current treatment guidelines. The results of the review suggest that primary care nurse practitioners must be up-to-date on the latest treatment guidelines, evidence-based practice, and options for treatment for children with ADHD (Salmeron, 2005). Salmeron discussed the significant social and academic impairments in children with ADHD. Salmeron also reviewed several studies that discussed significant family conflict in families with children that have ADHD, both diagnosed and undiagnosed. Salmeron indicated that the primary care nurse practitioner must possess the knowledge and ability to counsel and educate families with children who present with ADHD symptoms.

Goodman (2010) also conducted a similar review of articles discussing the diagnostic criteria for ADHD and the pharmacotherapeutic treatment of ADHD. The article summaries included diagnostic criteria according to the American Academy of Child and Adolescent Psychiatrists (AACAP) based on modified diagnostic criteria from the DSM IV-TR, and guidelines recommended by the American Academy of Family Physicians (AAFP). Goodman noted the inconsistencies in the diagnostic criteria as a barrier to effective and consistent treatment of ADHD in the pediatric population. Goodman also presented a summary of previous research showing the neurobiological difference between children with ADHD and those without ADHD including summaries of two studies that noted differences in EEG activity when comparing children with ADHD

to those without. Goodman also presented summaries of three studies validating ADHD as an established and valid psychiatric disorder by demonstrating the effectiveness of pharmacotherapeutic and non-pharmacotherapeutic interventions for children with ADHD. Recommendations included that primary care providers be up-to-date on the latest treatment guidelines and therapy options for families with children who have ADHD and providers treat ADHD as a valid medical diagnosis.

Treatment of ADHD in children and adolescents.

McLeod et al. (2007) conducted a non-random, quasi-experimental retrospective quantitative and qualitative study of 1,139 respondents to a national survey that included yes/no questions about ADHD and the pediatric population. An unknown number of the study parent participants also answered an open-ended question about what they knew about ADHD. The goal of the study was to better understand public knowledge about ADHD in children. Sixty-four percent of respondents had heard of ADHD and 77% were unable to accurately describe symptoms of ADHD. Seventy-eight percent of respondents who had heard of ADHD believed it was a real medical condition, and of those, 65% believed counseling and medication was the most effective treatment choice for ADHD (McLeod, et al., 2007). McLeod, et al. concluded that the general population in the United States was poorly informed about ADHD in children and adolescents and recommended future research focus on the public recognition of ADHD signs and symptoms, and react to children who displayed signs and symptoms of ADHD.

Corkum et al. (2005) conducted a double-blind, randomized trial evaluating enrollment adherence to treatment plans including stimulant and placebo therapy combined with parent training and support. Corkum, et al. included a quantitative descriptive study of parent perceptions of ADHD and opinions about pharmacological

and non-pharmacological treatment modalities. Parents who were more knowledgeable about ADHD were more likely to adhere to treatment plans that included parenting support and training, but not medication therapy for their children with ADHD. Corkum et al. recommended that practitioners educate families about ADHD signs, symptoms, and causes prior to offering treatment options. The authors suggested that future research should explore the barriers to treatment adherence.

Johnston et al. (2005) conducted a quantitative quasi-experimental study investigating the experiences and treatment choices of parents with 5 to 15 year old male children diagnosed with ADHD. The authors used validated questionnaires, including a treatment history questionnaire, ADHD beliefs scale, and written analogue questionnaire with descriptive statistics to analyze data. Ninety-seven percent of parent participants used behavioral management, 81% also used medication, and 52% used natural alternative treatment including vitamins and diet modifications. Twenty-nine percent tried individual child therapy and 19% tried family therapy. Parents most strongly endorsed behavioral modification and medication management to manage their child's ADHD symptoms. The majority of parents believed ADHD had a biological cause (Johnston et al., 2005). The accuracy of parents' beliefs regarding the cause of and efficacy of treatment for ADHD positively correlated with parents' decision to seek treatment. Johnston et al. (2005) recommend primary care providers communicate with families to understand parents' beliefs and perceptions of ADHD and provide families with treatment choices and accurate information about the diagnosis and cause of ADHD.

Miller-Horn et al. (2008) conducted a retrospective, randomized controlled trial comparing the relative effectiveness of five different medications commonly used to treat

ADHD in children and adolescents. Data were gathered over a two-year period from 110 parent participants, and outcome measurement of behavioral improvement included the subjective, categorical assessment by the participant's physician. Treatment options included amphetamine/dextroamphetamine extended release, amphetamine/dextroamphetamine, osmotic controlled release methylphenidate, atomoxetine, and methylphenidate. The authors found that 78% of participants experienced symptom improvement with medications. No statistical difference was observed in the difference of efficacy between the five medications.

ADHD and family experiences and perceptions.

Ghanizadeh (2007) conducted a qualitative descriptive survey of 19 parents with children who had been diagnosed with ADHD to better understand parents' perceived barriers to treatment, source of information about ADHD, reason for treatment delay, and the first person who suggested the diagnosis of ADHD. Ghanizadeh conducted personal interviews with parents and their children and also had requested parents fill out a questionnaire about their knowledge and attitudes towards ADHD. Parents reported that they received information about ADHD from mass media (85.8%) with 9.52% of information coming from medical professionals (Ghanizadeh, 2007). Teachers first suggested ADHD to parents 34% of the time. Family members first suggested ADHD to parents 27% of the time. General practitioners first suggested ADHD less than 5% of the time, and pediatricians 6% of the time. Parents reported delays in seeking treatment after being made aware of the possibility of ADHD in their children. Forty-one percent of parents did not know where to refer their child, and 14.4% of parents did not feel their child needed treatment. Twenty-two percent believed the symptoms would resolve spontaneously (Ghanizadeh, 2007). Ghanizadeh found that barriers to ADHD treatment

were significant, with the most significant barrier being a lack of parents' understanding of the clinical diagnosis and treatment recommendations. Ghanizadeh recommended that general practitioners and pediatricians ask parents about their child and ADHD and educate and counsel parents about ADHD.

Bussing et al. (2006) conducted a combined quantitative and qualitative study of parent-initiated self-care for their children with ADHD symptoms. The authors conducted a longitudinal cohort study of ADHD symptom detection, use of services, and parents' self-care strategies, and analyzed data by statistical regression. The authors also used open-ended questions to better understand the experience of parents who choose self-care for their children with ADHD symptoms. Qualitative data were analyzed by Spradley's method. Behavior modification was the primary method used by parents who chose self-care for their children (99% of study parent participants). Sixty-three percent (n=167) of the children in the survey did not receive professional treatment for their ADHD symptoms compared to 51 who were treated by mental health professionals and 48 by general practitioners. Bussing et al. found that the majority of parent participants did not seek treatment for their children with ADHD symptoms and tried behavioral modification at home. Decisions to try self-care were strongly related with gender of child (male > female), race (Black < White to seek professional treatment), and socioeconomic status. Parents also refrained from seeking professional treatment for their children with ADHD, because parents felt familiar and knowledgeable about ADHD treatment. Bussing et al. recommended more effective culturally competent, community-based, family focused programs to assist parents with children who have symptoms of ADHD.

Carpenter-Song (2009) conducted a 13-month ethnographic study of the lived experience of behavioral and emotional disorders in families and children in the United States, through immersion with 19 families having children with various mental health disorders. Three families had children with only ADHD as a clinical diagnosis. Two families were White and one was Black. Carpenter-Song (2009) found the White families to attribute their child's ADHD to neurobiological differences and sought treatment for their child in early latency through their primary care provider. The Black family attributed their child's ADHD symptoms as behaviors, difficulties, and challenges, and only sought treatment after teachers suggested their child had symptoms of ADHD. The White families were more likely to employ confidence in stimulant therapy to help manage their child's symptoms, while the Black family chose to self-treat through behavioral modification. Carpenter-Song noted significant differences between ethnicity and race, and the perception of ADHD related to cause and treatment modalities. Carpenter-Song concluded that family' perceptions, beliefs, and desire to seek treatment or self-treat their children for ADHD symptoms were related to their unique past experiences, cultural considerations, and frequency of contact with medical professionals.

Kendall et al. (2005) conducted a qualitative descriptive study using unstructured interviews and demographic questionnaires to understand the experience of service use for families of children with ADHD. A sample of 157 mothers self-identified as African American (31%), Hispanic (36%), and White (33%) participated in the study. Kendall et al. suggested that ADHD is a universal experience and service needs are a function of social and demographic factors. Single-mother families use the most services, Hispanic families used the fewest services, and families of boys with ADHD used more services

than families of girls with ADHD (Kendall et al., 2005). Services used included counseling, school services, and auxiliary services. School services were accessed most (46.7% of parent participants) followed by counseling (35.7%). Sixty-eight percent of respondents reported that their child was currently taking medications that were at least “a little helpful” (Kendall et al., 2006, p. 279). Thirty-eight percent of parent participants had unmet service needs. Kendall et al. recommended detailed family assessment and intervention matching to better serve the individual needs of each family. Schools, providers, nurses, and counselors should coordinate and advocate for families with service needs to match the need to the specific family (Kendall et al., 2006).

Literature Gap

Much research exists about ADHD medication efficacy and options (Bloom & Cohen, 2007; Dopheide, 2009; Engler, 2008; Goodman, 2010; Johnston et al., 2005; Miller-Horn et al., 2008), treatment modalities in children and adolescents with ADHD (Bloom & Cohen, 2007; Corkum et al., 2005; Engler, 2008; Goodman, 2010; Johnston et al., 2005; McLeod et al., 2007; Salmeron, 2009), and family perceptions and beliefs about ADHD (Bussing et al., 2006; Carpenter-Song, 2009; Corkum et al., 2005; Cunningham, 2007; Kendall, 2007; McLeod et al., 2007). Research also exists regarding the economic impact of childhood ADHD on healthcare systems (Engler, 2008; Salmeron, 2009), and provider perceptions, abilities, and comfort with treating children and families with ADHD (Engler, 2008; Ghanizadeh, 2007; Goodman, 2010; Miller et al., 2005; Miller-Horn et al., 2008; Poncin et al., 2007; Salmeron, 2009, VanCleave & Leslie, 2008). There is currently a gap in research that explores the process by which families seek treatment for children with ADHD.

Chapter Summary

Glazer and Strauss' grounded theory (1967) was the theoretical framework that guided this study. Research from prior studies indicated that ADHD is a diagnosable medical condition with a relatively high prevalence in the child and adolescent population. Treatment of ADHD in children and adolescents is common and focuses on therapy and pharmacotherapy. Experiences and perceptions of families with children with ADHD are variable and unique to each family. Social, cultural, and financial differences between families significantly affect family experiences and perceptions of children and ADHD. This study was conducted because of the gap in the literature related to the process of seeking treatment for families of children with ADHD.

Chapter III

Methodology

The purpose of this study was to explore the process by which families seek treatment for children with ADHD. In this chapter, the study design, population, sample, setting, data collection instruments and procedures, data analysis procedures, and limitations of the study are presented. Naturalistic, qualitative descriptive methods were used with a convenience sample of adult family members/parents of children diagnosed with ADHD. Parent participants were recruited from a Midwest pediatric and adolescent mental health outpatient clinic. Descriptive naturalistic inquiry was appropriate for this study because this method provided a rigorous and systematic description of the process under investigation. The researcher conducted face-to-face personal interviews to elicit information from parent participants. Colaizzi's (1978) method of data analysis was used to analyze the raw data.

Design

The design was a qualitative design using ground theory methodology. This inquiry was appropriate for this study because the goal was to understand the process of families seeking treatment for children with ADHD. This methodology allowed the researcher to explore, analyze, and describe the process by which families seek treatment, providing an accurate and unbiased explanation of the process of seeking treatment for children with ADHD. Qualitative descriptive inquiry allowed the researcher to better understand how families seek treatment through understanding families' unique experiences of the process of seeking treatment, expanding the existing knowledge

base of family experiences of the process of seeking treatment for children who have ADHD.

Population and Setting

The target population for this study was families who sought treatment for children diagnosed with ADHD. The sample was a non-random convenience sample consisting of seven families. Parent participant eligibility and criteria for sample selection included the following family and child characteristics.

Eligibility criteria – Family.

The family had to consist of at least one adult, 18 years of age or older, able to speak and read English, without cognitive impairment, and be one of the following: a biological parent, stepparent, foster parent, or otherwise legal guardian of the child; had at least one child diagnosed with ADHD; both adult and child lived in the same residence and shared the same U.S. Postal Service mailing address.

Eligibility criteria – Child.

The child was at least 8 years of age and less than 18 years of age, able to speak English, male or female, and be formally diagnosed by a licensed therapist, licensed counselor, advanced practice nurse, medical doctor, or psychologist with ADHA according to the DSM IV-TR (2005) criteria; must not have had any other mental health diagnosis on Axis I of the five axis diagnostic method according to the DSM IV-TR nor have cognitive impairment.

Setting

The setting for identification of parent participants was an outpatient child and adolescent mental health clinic in the Midwest. Children diagnosed with ADHD were identified by chart review with the guidance of the mental health clinic manager, who was the key informant for accessing contact information for this study.

The clinic provides therapy and medication management to approximately 800 children and adolescents. The clinic staff consists of three licensed family and child mental health therapists, two board-certified child and adolescent psychiatrists, and one registered nurse.

Data Collection Instruments

Data were collected through a demographic questionnaire, consisting of adult and child sections, and unstructured personal interviews. Only the adult parent participant completed the demographic questionnaire (Appendix B). For the purpose of this study, the child was not requested to fill out a demographic questionnaire or participate in the personal interview, nor did the researcher have personal contact or communication with the child.

The adult section of the demographic questionnaire comprised information, including family income, gender, ethnicity, geographical location, type of insurance, family size, relationship to child, highest level of education completed, age range, marital status, employment status, number of children in the home, and number of adults in the home. The child section of the demographic questionnaire consisted of the child's age at diagnosis, age at which adult first thought child had ADHD, professional who

diagnosed child with ADHD, what type of schooling the child receives, if the child takes medication for ADHD, and if the child is in therapy for ADHD.

In-depth personal interviews were conducted using open-ended questions to investigate and explore how families sought treatment for their children with ADHD. The opening question for the interview was, "Please tell me about the process of seeking treatment for your child with ADHD." This question was followed by the appropriate probing questions depending on the parent participant response. A sample probing question included, "Please tell me more about the process of seeking treatment with your pediatrician after the teacher told you your child may have ADHD." This method allowed for the collection of parent participants' detailed and rich descriptions of their experiences.

Trustworthiness of the data was demonstrated through enhancing credibility, dependability, and confirmability. Credibility was maintained through member checking. The researcher shared emerging themes with the first parent participant, a parent participant midway through the interviews, and the final parent participant to see if findings were true to their experiences. The researcher also shared the transcribed interviews with two parent participants to verify that what was said in the interview reflected what the parent participant intended to communicate to the researcher. Credibility was also enhanced by peer scrutiny of the manuscript by a nursing faculty advisor. Dependability was enhanced through attempting to triangulate the findings of the study with a diverse population of parent participants; although was not achieved because the sample was not sufficiently diverse. The researcher enhanced confirmability through detailed field notes and creating an audit trail (Shenton, 2004). The audit trail consisted of a binder with individual sections for raw data, individual line

coding, researcher notes illustrating the emerging themes, and a section outlining in flow chart format the relationship between the themes and the emergence of a core variable. The researcher used envelopes labeled with emerging themes and physically cut out portions of raw data containing quotes supporting the themes in each envelope. The researcher requested that two other student colleagues review the findings to test the transferability of the results.

Confirmability was enhanced through the use of journaling to explicate beliefs and identify possible thoughts, ideas, presuppositions, and personal biases related to the topic of inquiry. Journaling gave the researcher a frame of reference prior to conducting the study and helped the researcher approach the topic in an honest and open manner. The researcher also used bracketing, or suspending judgment, by putting aside the researcher's personal beliefs and refraining from making judgments about the observations and data. Bracketing was used continuously throughout the study to assist the researcher with self-reflection and awareness. Bracketing consisted of a journal where the researcher entered personal thoughts and feelings emerging from each interview. The researcher continued to journal during data collection and coding, constantly reviewing the journal, comparing personal thoughts and feelings with the emerging themes, attempting to enhance the objective nature of data interpretation with efforts to prevent personal thoughts and feelings to become part of the data set.

Data Collection Procedures

Data were collected after obtaining permission from the University of Wisconsin Oshkosh Institutional Review Board (IRB) Protection of Human Participant Committee.

The clinic manager identified potential parent participants through chart review at a Midwest outpatient child and adolescent mental health clinic according to the eligibility criteria. Parent participant data were collected from an independent clinic; the clinic director was the person who approved for the agency. The clinic manager provided the researcher contact information of parents of children with ADHD. The researcher contacted potential parent participants by mailing a parent participant letter of informed consent (Appendix D) with a self-addressed stamped return envelope. Potential parent participants signed and returned the consent forms indicating their approval to participate. Informed consent was signed prior to the interview. The researcher did not have access to identifying information of the children of the parent participants. The clinic manager provided only the contact information for the adult parent participant.

Data were collected by audio taped, face-to-face interviews and detailed field notes. The parent participant chose the location and setting of the interviews to ensure confidentiality and comfort in disclosure. Three interviews were conducted in the parent's private residence, and the remaining interviews were conducted at the parent's place of employment. The researcher requested that only the adult be present during the interview (and significant other if desired) to protect the privacy and identity of other family members. The researcher conducted a pilot interview with one parent prior to data collection to assess the open-ended question and, in general, the interview process. The pilot interview helped the researcher gain insight as to the appropriateness of the opening interview question and allowed practice in developing appropriate probing questions, while validating with the pilot parent participant that the data elicited during the interview was congruent with the process that the parent was explaining.

Data were numerically coded so that no identifying information was accessible to the researcher. All data collected were stored in a locked filing cabinet in the researcher's home office to ensure confidentiality.

Data Analysis Procedures

The researcher used Colaizzi's (1978) method of qualitative data analysis, as outlined in Speziale and Carpenter (2007) to analyze parent descriptions of the process of seeking treatment. Verbatim transcriptions of the interviews were read and re-read, and significant statements were extracted from each interview to identify meanings. Meanings were organized into themes and an exhaustive description of the meanings and themes are presented. For example, under the theme *getting started*, the subtheme *finding out* emerged from raw data, such as the following quotation.

Well it started back when he was about five years old. I think we, my husband and I, always knew there was some underlying issue. So, we talked about what it could be and couldn't be, and ultimately decided we had to start somewhere, so we called our doctor to make an appointment. That's pretty much how it all began.

The researcher coded next to these raw data and included written words, including knowing, talked about, decision making, starting the process, beginning the process, and first finding out. These comments were later included under the theme *getting started*, and more specifically, the subtheme *finding out*. The raw data was included in the exhaustive description of the subtheme *finding out*, with other quotes from other interviews that supported this theme and subtheme. The researcher validated the descriptions with several of the parents by e-mailing the parents the

transcribed interviews and asked if the transcriptions were congruent with the information that the parents had shared during the interview. Any new data revealed during validation was incorporated into the exhaustive description. Demographic data were analyzed using descriptive statistical methods.

Limitations

Limitations included:

1. A small, non-random convenience sample was used.
2. Transferability is limited as parent participants were identified from only one outpatient child and adolescent mental health clinic in the Midwest, limiting the generalizability of the study.
3. The researcher had very limited fiscal reserve to conduct this study.
4. The researcher had a time limit of approximately 8 months to complete this study.
5. There was possible researcher bias with researcher as the instrument.

Chapter Summary

This study used a qualitative descriptive naturalistic inquiry to provide a rich description of the process by which families seek treatment for children with ADHD. Approval was obtained from the University of Wisconsin Oshkosh Institutional Review Board prior to data collection. A non-random convenience sample from a Midwest child and adolescent mental health outpatient clinic was used to obtain parent participants. Unstructured, face-to-face interviews were conducted with open-ended questions that provided a detailed description of the process of seeking treatment for children with

ADHD. Collaizi's (1978) method of data analysis was used to identify themes with an exhaustive description of the process of seeking treatment for children with ADHD.

Demographic data were collected and analyzed using descriptive statistics. Limitations of the study included transferability of the data due to the geographical location of the study and the small number of parent participants in the study.

Chapter IV

Results and Discussion

The purpose of this study was to explore the process by which families seek treatment for children with ADHD. Additionally, it was hoped that an understanding of this process would enable advanced practice nurses in primary care to better assist, understand, and treat patients and families of children with ADHD in primary care.

The results of this study are presented in this chapter. Themes and sub-themes were identified from the interviews with parents using GT as a theoretical framework, and Colaizzi's method for data analysis. The overarching theme was *Journeying to Make Meaning of ADHD*. Four major themes, encompassing several sub-themes, were identified for the parent participants. These four themes included: (a) *getting started*, (b) *gathering information* (c) *understanding*, and (d) *following through*. Within the *getting started* theme, *parent suspicions* and *finding out* were identified as subthemes. *Seeking advice, back and forth*, and *reassurance* were identified as sub-themes in the second theme of *gathering information*. The subthemes *perspectives* and *medications or not* were identified for the third theme *understanding*. *The end is relative* and *crossing the bridge* were identified as sub-themes in the fourth theme *following through*.

Demographics

The parent participants were recruited from a local outpatient child and adolescent behavioral health clinic in the Midwest. The clinic manager identified 25 eligible parent participants. Seven of the 25 were successfully contacted by the researcher and participated in the study. One of the parents participated in a pilot

interview. The pilot interview was not included in the data set. Nine of the remaining 18 eligible parent participants declined to participate. The researcher was unable to personally contact the remaining 9 eligible parent participants for multiple reasons. Telephone and mail contact was never established with this group after multiple attempts. Table 1 contains the parent demographic information.

Table 1

Family Characteristics as a Percentage of Sample

Characteristic	Percent	Frequency
Gender		
Male	33.3	2
Female	66.7	4
Relationship to child		
Parent	100.0	6
Marital Status		
Married	83.3	5
Divorced	16.7	1
Number of adults in home		
1	16.7	1
2	66.7	4
3	16.7	1
Parent age		
31 – 35	33.3	2
36 – 45	33.3	2
46 – 50	33.3	2
Education level completed		
High school/equivalent	16.7	1
Bachelor's degree	33.3	2
Master's degree	50.0	3
Self-identity		
Caucasian/White	100.0	6

Table 1 (cont)

Characteristic	Percent	Frequency
Family income		
\$35,000 - \$49,999	16.7	1
\$50,000 - \$64,999	16.7	1
\$65,000 - \$79,999	16.7	1
>\$80,000	33.3	2
Would rather not say	16.7	1
Employment status		
Employed full-time	83.3	5
Employed part-time	16.7	1
Demographic location		
Urban	50.0	3
Suburban	33.3	2
Rural	16.7	1
Total children in family		
2	66.7	4
3	16.7	1
4	16.7	1
Type of insurance		
Commercial	100.0	6

The majority (67%) of parent participants were female, and all parent participants were the parent of the child. Eighty-three percent of parent participants were currently married, with two adults living in the home. Parent age ranged from 33 to 47 years. Half (50%) of the parent participants were educated at a graduate level and one-third had a bachelor's degree. All parent participants identified themselves as Caucasian/White. Family income ranged from \$46,000 to \$110,000. Most of the parent participants were employed full-time and none of the parent participants were unemployed. Half of the

parent participants resided in an urban setting. Two-thirds of the families had two children, one family had three children, and one family had four children. All of the families held commercial insurance.

Parent participants also provided demographic information for their child with ADHD. Table 2 contains child demographic data, as reported by the parent participant. Four of the children were male and two were female. The majority (67%) of parents first thought their child had ADHD when the children were between 6 and 10 years old. Two children had ADHD for 1 to 2 years, two children had ADHD for 3 to 4 years, and two children had ADHD for more than 4 years. A psychologist diagnosed half of the children with ADHD, a medical doctor diagnosed one child, and both a medical doctor and a psychologist diagnosed one child. Half of the children were currently taking medications for ADHD.

Table 2

Child Characteristics as a Percentage of Sample

Characteristic	Percent	Frequency
Gender		
Male	66.7	4
Female	33.3	2
Age parent first through child had ADHD		
3 – 5		
6 – 10	16.7	1
11 – 14	66.7	4
	16.7	1
Age child diagnosed with ADHD		
6 – 10	83.3	5
11 – 14	16.7	1
How long has child been diagnosed with ADHD		
1 – 2 years		
3 – 4 years	33.3	3
>4 years	33.3	3
	33.3	3
Who diagnosed child with ADHD		
Doctor	16.7	1
Psychologist	50.0	3
Doctor (MD/DO) & Psychologist	16.7	1
Child on ADHD medications		
Yes	50.0	3
No	50.0	3

The Interview Process

All seven parents were contacted via mail and telephone by the researcher to discuss the study and ascertain interest in participating. The researcher and the parent participant then negotiated a time and place to conduct the interview. Each interview was conducted in the parent participant's setting of choice. All interviews were face-to-

face. Four interviews took place in the parent participant's homes and three interviews took place at the parent participant's place of employment. Informed consent for participation and audio-taping were obtained prior to initiating the interview (Appendix C). All interviews were conducted in private with only the parent participant and interviewer present.

Parent participants were encouraged to share only the information they were comfortable sharing. Each parent participant was given time for debriefing after the interview. None of the interviews were terminated early, nor did the parent participants exhibit any undue emotional reactions during the interview.

Results

Each parent participant described unique and individual processes related to seeking treatment for their child with ADHD. There were some similarities evident with the analysis of data. Four themes were identified with numerous subthemes (Table 3).

Table 3

Themes and Subthemes

Overarching Theme	Major Themes	Subthemes
Journeying to Make Meaning of ADHD	Getting started	Parent suspicions Finding out
	Gathering information	Seeking advice Back and forth Reassurances
	Understanding	Perspectives Medications or not?
	Following things through	The end is relative Crossing the bridge

Theme One: Getting Started

All parent participants described the process of seeking treatment as having a starting point. One parent described the beginning of the process,

It starts back, first of all for me, it was a realization that my child might have ADHD. I think, really, it took a discussion with my wife to say, well, something is going on here. Where do we start? We have to start somewhere, you know? So yeah, I can definitely remember there was a distinct time and place where I realized we were starting a new phase, something was different and I started talking about what to do, and, you know, we decided we had to start somewhere.

Another parent described that the beginning of their process of seeking treatment occurred when she started to get comments from others.

We always knew he was an active little boy, you know? Then we started to get comments from family, friends... hinting at ADHD. Stuff like...maybe you should consider talking to someone, or other comments that made me think I maybe needed to start looking into this a little bit more.

Other parents described similar experiences with the process of getting started.

Following is one example.

Well it started back when he was about five years old. I think we, my husband and I, always knew there was some underlying issue. So, we talked about what it could be and couldn't be, and ultimately decided we had to start somewhere, so we called our doctor to make an appointment. That's pretty much how it all began.

And yet another parent described the experience and process of getting started with treatment for his child with ADHD through recognizing gradual changes in his child's behavior.

It kind of started for me when I had this kind of a-ha moment where everything just seemed to make sense. He was having difficulty in school, and teachers were sending notes home, but his grades weren't too bad. You know, stuff about attention and talking out of turn. I was just thinking that he is a normal boy, you know, umm...energetic, rambunctious, just normal boy stuff. But then I started to see his grades slipping, and he's getting in trouble more at school, and he's a good kid, you know? So we had a doctor appointment and I half-jokingly brought up ADHD, and the doctor asked me a few questions and got me thinking...so I started there, yeah, kind of made my mind up that I should look into this, and that's how it started, us seeking treatment.

Parent suspicions.

Within the theme *getting started*, parents noted that they started the process of seeking treatment because they had suspicions their child may have ADHD. One parent explained this discovery.

In about first grade we started noticing that she was a little scattered. I mean, she was always a happy go lucky kind of kid, but we started to notice differences between her behaviors and some of her friends. She seemed a little too energetic, you know? Just a little different than the other kids, so we started to get suspicious... does she have more going on than just being an active little girl? Thoughts like that. So we started to look into things a little more...talking to other parents, looking things up on the Internet, stuff like that. Stuff related to ADHD and behaviors and that sort of thing.

A second parent described the process of recognizing that their child may have ADHD.

He was... always really active...always. We knew his medical background and stuff like that, no big deal, everything's normal. He was always a kind of a high strung little kid. So you don't notice or try to adapt to it. ...playing at home, it's no big deal. However as he got into school we noticed he started having difficulty with little things and corralling his energy to work on homework. Around 2nd grade I started to think that maybe something was up. Something like ADHD, but I didn't know what that was all about. So I started to do some research on the Internet, you know, stuff like that. I kind of realized then that maybe we should talk to someone...

Another parent participant described the moment she and her husband began to consider that their child may have ADHD.

We knew...we just always knew, looking back. My husband... had it when he was younger, now looking back. So we were seeing the same things with him... we noticed that he wouldn't sit still at the dinner table, or watching a movie, and being teachers we just had that suspicion, even though we were in kind of a denial. So we decided it would be best to start looking for confirmation, so we decided to talk to his pediatrician at one of his appointments.

Finding out.

The second subtheme related to the theme *getting started* included the process of parents finding out their child may have ADHD. Several parent participants revealed that the process of seeking treatment started when a teacher informed them that their child was displaying signs, symptoms, or behaviors of ADHD.

In first grade her teacher noticed something very different about how she was learning and processing information, and she thought that we should have an evaluation. She explained that she has seen children with ADHD and our daughter fit that bill. So we decided, you know, based on the teacher's comments and recommendations, to talk with our pediatrician about it.

Another parent discussed finding out that there was a possibility her child had ADHD after receiving several report cards and notes from her child's teacher.

He had half-days in a kindergarten class. And it was, you know, I was hearing all the inattentive stuff and seeing it on report cards, but nothing of, you know, when they said, I think he has ADHD, and they'd be like, well, you know it's pretty common...so I started to ask what I could do from there, like, do I see a doctor? Do I work with the teacher? Is this what's really going on? What do I do now?

So I kind of had questions and was surprised...but the school was helpful and we worked together to get help.

Yet another parent described her realization that her child may have ADHD through an interaction with the teacher.

It began when she was in fifth grade...and her teacher had a different teaching style. ...I went to school because the teacher was asking about behaviors and other things that I was getting concerned about, and she said your daughter has ADD and needs medication. Which, she just bluntly came out and said it, which was a big surprise to me... and I was open to listening and asked her why she believed what she did, and she was stating that she gets distracted and she has trouble staying on task...and we talked about it and so that was the beginning of treatment.

Theme Two: Gathering Information

When describing the process of seeking treatment for their children with ADHD, several parents noted the process of gathering more information about ADHD was necessary. The parents noted this was done through consultation with their child's healthcare providers, teachers, and the parent's own peers and friends. Three main subthemes were noted encompassing this theme including *seeking advice, back and forth, and reassurance*. A parent described a typical scenario below.

Well the process itself is ongoing, but we definitely needed to gather enough information so we could make a decision on what to do and feel more comfortable with the possibility of starting medications, or working with school to

do what they needed to help...and of course just for peace of mind that you are doing the right thing for him.

Another parent noted the importance of being assertive and constantly seeking information during this process through self-help written books and attending seminars, as well as keeping lines of communication open between school and the healthcare provider.

We went to... meetings, that helped. I went to ... meetings I should say, and got the information from... I can't remember if a doctor came and spoke from Madison about ADHD, but I know I learned a lot...I read a couple books, asked the doctor and psychologist for good resources, so I got the name of a couple books and some websites. So you have to ask questions and get that reassurance, so you know you're doing the best thing for child.

Seeking advice.

Parents also revealed that they sought advice during the process of seeking treatment for their child. Parents all sought professional and peer advice regarding treatment of their children. Many parents initially went to their family practitioner or pediatrician for help. One parent described this process.

...So we took him to our family physician and said, what are your experiences? What do you know about ADHD? And we, kind of, shopped to make sure our physician knew something about this before we just walked in and said, okay, at this point just give some medicines and see what happens. So, we found a physician in town here, who's good at that. Then we went from there.

Another parent described the process she took when seeking advice from her family practitioner.

We just went straight to our pediatrician after the teacher brought up her concerns and recommendations to see the doctor. We just sat down and said, look, this is what's happening. Do you think he has ADHD? What should we do? Then the pediatrician offered to start medications and just go from there. So, yeah, we needed to get more information and advice on what to do next.

Most parents went to their healthcare provider first to get advice, recommendations and information. The following parent described the process of seeking advice.

So we went to our pediatrician for advice who then had us fill out some questionnaires and recommended we have more testing done by a psychiatrist. But overall, we were really happy because the doctor talked to us about ADHD and answered questions about medications and what might happen and all that. We really felt more comfortable with getting testing done and knowing that she was going to be okay, we would figure this out and do what we needed to do.

Back and forth.

Another subtheme related to the theme gathering information included the process parents underwent while seeking treatment of going back and forth between their child's teacher, the family physician, and psychologist. One parent described this process as tedious and frustrating.

...So after the teacher brought things up we went the route of ADHD. Then we went to the doctor, who had us fill out some questionnaires, then sent us back to school to have the teachers fill out more forms, so it was like, back and forth, back and forth, until finally the doctor said he had ADHD, then we had to talk about what to do next. It was frustrating, you know, doing all that because they

don't explain everything right away, and you don't know how long this process is going to take or when they will start to actually help him.

Another parent participant shared his experience communicating with the school, physician, and the psychologist.

...Next we decided to see the school psychologist who was recommended by the teacher and one of the parents at school. So there was that testing, then the recommendation to see our physician, but we were also told we could see a child psychologist for more testing. So were given a few options. We went back and forth like this for a while, the psychologist at school, our doctor, then decided to finally get testing done by psychologist. This all takes time, you know, and the whole time our son still was not being treated.

Yet another parent described the process of communicating and going back and forth between the physician, school, and a clinical psychologist.

...So we made an appointment with the pediatrician to start, because we really didn't know who else to start with. We took him to the pediatrician, and she immediately said, well, you need to go to one of the psychologists...and then we had to make a follow up after that to discuss... medication and what were going to do. We had to give forms to the teacher, the principal, fill out this, that. Then we finally met back with the psychologist for the diagnosis, explained to the school were working on things, and finally back to the pediatrician for medications. What could I do? You know, you just do what they recommend and follow the steps to help your child.

The parent discussed the process when looking back at what she had to do.

But yet, it was something that was, it was a blessing in disguise, honestly. What it gave us was peace of mind, truly. We took every step that they gave us and looking back it was okay to jump through all the hoops because in the end everyone was on the same page, and it really was all about her in the end.

Reassurance.

Another subtheme significant to the theme of gathering information was that of reassurance. Most parent participants described the process of seeking reassurance as necessary and helpful to the overall process of seeking treatment for their child with ADHD. One parent describes this below.

So it was doctor...who is his pediatrician that really helped us. He helped me understand this better and understand him better. He told us that, you know, this is not a big problem and won't really matter in the long term, he has a good family, good friends, tries hard. He also explained things to us so it made sense to me, helped me understand everything better, you know, that it's an ongoing thing, there's different ways to go about it. I think he was a good guide through all of this, even though he admitted that he wasn't a specialist in this.

Other parents noted that it was essential to the process of seeking treatment to have some reassurance and support from their physician and teachers. One parent discussed her experience of this process with her child's school.

His sixth grade teacher was great. We were going through this, and she was understanding, kept things positive, you know, kept saying how he wasn't a bad kid, wasn't a troublemaker, but that his ADHD was a real thing and did get in the way of his learning, even with his friends, they noticed it too, and he was self-

conscious of it. So having that is important, helps you with knowing that this will be okay, that you will eventually get this figured out, to keep doing what you're doing.

Another parent described the importance of reassurance in the process of seeking treatment for her child with ADHD.

I think, the only thing that I would say on the professional end of it, that just reassurance from the provider in the beginning and throughout the entire process...I'm going to do this, this is what you can do, you know, that kind of thing. The commonness of it and stuff. It was more like, that's what you think it is, okay...but I think the process was efficient and helpful, there wasn't a lot of, what do we do ifs and that...

Theme Three: Understanding

When asked about the process of seeking treatment for their child with ADHD, many parents identified that understanding is essential. One parent remarked, "I think it was really important to be able to understand everything that was going on...you need to make good decisions with good information so you don't hurt your child or make things worse."

Perspectives.

Within *understanding*, parent participants identified different aspects of understanding including different perspectives of the process of seeking treatment. For example, one parent discussed the different information she received from the different professionals working with her and her child, and how these perspectives impacted her decisions during the process of seeking treatment.

... after the teacher just bluntly told us she had ADHD, and that she needed medication, this was a very big surprise to me. And I was open to listening and asked her why she believed what she did, and she was stating that she gets distracted and has trouble staying on task.

This parent continued to discuss the importance of perspective by noting what the psychologist recommended.

... after all the testing we met with the psychologist, and he explained to us that she did have a slight case of ADHD, so we could choose what to do, and I asked, from his perspective, if this were his child what would he do, and he said, I would probably hold off on medication right now. So this was also something to consider. Then we went to our doctor who supported our decision to hold off on medications and try some other stuff first. I think you really need to listen to everybody involved, good and bad, then make decisions with all of that considered.

Yet another parent described the significance of gaining perspective to facilitate the decision making process of seeking treatment for his child.

... the teacher was very young. So the same thing, she wouldn't call us or talk to us about it. It just kept coming home on his report card in comments, that he had symptoms of ADHD... then I requested the pediatrician refer us to a psychologist because I work in the school system and know how things work. So I wanted an accurate assessment, so I could make a decision on what to do and if there was more going on than just ADHD... even the pediatrician agreed that we should consider medication in the meantime and offered a couple different things, but we wanted to wait until we saw the psychologist... it was just really important to

get everyone's professional opinion, to know what to do, the more you know, you know? So our choices for treatment were based on everyone's input.

Medications or not?

All parents in this study were confronted with the topic of medication use for their child with ADHD during the process of seeking treatment. Parents identified the decision to use medications as a significant step in the process of seeking treatment for their child with ADHD. A parent described this decision.

We started talking to his pediatrician. We agreed to start a medication, he gave us some information, told us that this was typical treatment and it may or may not work, that we might have to play around with the doses and stuff until we found the right fit for him. We trusted the doctor, so we went ahead and started medication. That was a turning point in his treatment, you know, pretty significant, actually. We finally got to the point where we were doing something about his ADHD, not just going to people, getting sent here and there, you know, but actually treating him.

A parent discussed the process of choosing to medicate his son with ADHD.

Yeah, we finally decided we had enough to go on and agreed to start medications. We tried a couple different medications. We tried, you know, we went to a chiropractor, and tried different behavior things with him. We tried all crazy things, you know, with soda in the morning, and anything we could try to see what work, you know, natural remedies too. And finally settle in on, you know what, we really need to medicate him to get him to perform the way he needs to... it wasn't anything we could do with environment, or behavior stuff, it

wasn't a parenting issue anymore. It was more of a chemical issue for him and medication worked.

Yet another parent described the process of choosing medication management as part of the process of seeking treatment for her daughter with ADHD.

... ADHD, and he recommended medication...that played a huge role, the decision to start the medication. So I asked him what he would do, and he suggested we try something, as far as a medication. So, I cried, and said okay, we're going to put her on medication. It has helped though. We've changed a few times, but overall she is doing well, and she still fidgets and stuff, but this is an ongoing process, and I understand that things will change, you know, as she grows and progresses through the grades...

Other parents chose not to medicate their children with ADHD. Here a parent described the process of not choosing medication for her child.

Even after she was tested I wasn't just going to put her on some medicine like some people do. It was like, no, we want to do the right thing. So, then we tried to keep her off sugar or some people said that caffeine works the opposite for kids with ADHD and ADD. We tried Coca Cola... also using some of the suggestions from the doctor and school like writing down lists, and take things more slowly, try to understand her better, ask the teacher to do what is best in the classroom, like placing her near the front, stuff like that. So I think that you need to know enough about it, understand it the best you can, so you can make the best choice about treating that works for you, you know?

Another parent discussed the process of choosing medications then deciding to stop using medications for his child with ADHD.

... We had put him on medication that was recommended by the psychologist...he ended up having, the side effects became, you know, different things, like ticks and stuff like that. He was blinking his eyes and stretching his mouth. I didn't like this so we decided to just stop the medications... We just accepted that he is who he is, and we choose to just live with it, you know. We tried the whole medication thing, and it wasn't for us. He was just, like, a zombie. So we would rather have him the old way... so our decision to start then stop medications was based on the experience we had, plus we didn't see any real reason to cause him these side effects and get made fun of and stuff. I finally came to the understanding that this is just the way God made him and we will deal with things as they happen.

Theme Four: Following Things Through

A recurring theme identified by the parents in the process of seeking treatment for their children with ADHD was *following things through*. One parent noted, "It is just a continuous process that you have to keep working on, you know, follow things through. This doesn't just go away, but changes all the time, so you just keep going."

Two main subthemes under the theme following things through were the *end is relative* and *crossing the bridge*.

The end is relative.

Parents described the process, as one parent states, "Having an end but not really, kind of a resolution that you've done all you can up 'till now, and just keeping up on things from there." Another parent describes the process up until the present time.

So I just...letting it take it's natural course...I'm not sure it ever ends, but you know, he's intelligent, and he does okay, so we came to the end of the medication stuff, but he continues to have a little bit of it, ADHD... you know, its all part of the little disorder, you know...for him and us. But, I think, as he gets older, you know, he starts to realize it more and starts to be able to help himself better, be in control, so its maybe an end for us but for him it might always be there.

Another parent shared a similar perspective about the continuous nature of the process of seeking treatment.

It is going through stages. You realize it, you get help, talk to everyone you can, you start medication, you follow up with the doctor and the school and you talk to him about it, see how he is doing, what he thinks, especially as he gets older. Its going through stages, one ends, another begins. It's all relative, you know? He's doing good, no problems in school, so you just keep things as they are, for now.

Crossing the bridge.

Another subtheme related to the theme following through is *crossing the bridge*.

A parent described the process of needing to seek future treatment for their child with ADHD.

So my worry was, we've been treating her since first grade, with medications, and when she really needs it in middle and high school what happens? So we decided, she's doing well now, succeeding. We'll just cross that bridge when we come to it. You just have to tell yourself that you take it one year, one day at a time. Things change, medications change, treatments change, so it is an evolving process, you deal with it as it comes.

Other parents discussed the process of continuously seeking treatment for their child, presently and in the future.

So it's an ongoing process...as they get older, more mature, physical changes.

All those things happen, so it's all our choice of what to do. We've been through it, and we know who to call and what to do. If things come up and we need help, we have a doctor who knows him and has worked with us. We know our options, what choices to make, so we just take it as it comes, but, yeah, it is definitely an ongoing process.

Another parent discussed the concept of seeking treatment in the future.

Because he's doing good right now, we've got it figured out. We'll just keep trying, worry about it if we need to...And he's stable, has good times, and I mean good days and bad days, but the bad days are a lot less, and aren't as bad...There isn't anymore what do we do if, now it's just knowing what to do when...go down that road when we come to it, I guess.

Overarching Theme: Journeying to Make Meaning of ADHD

All of the themes and subthemes identified in the data encompass the overarching theme of making meaning of ADHD through a journey. Throughout each theme and corresponding subthemes, parent participants identified the process of seeking treatment as a continuous process of exploration, learning, and making decisions. For example, one parent described the journey.

The whole experience, the way we went about it...it was almost like a journey for my husband and I. We were constantly learning about ADHD, looking at our

options, you know, weighing everything out, then deciding where to go from there.

Another parent identified a similar journey.

You know, we were just always trying to keep moving forward...from diagnosing and deciding on medications to getting help at school, to doing different things at home. We worked with school and the pediatrician, and of course our son too. We just kept moving forward, and sometimes backwards, going through this to try and understand what was going on, get answers, and try to fix whatever was wrong.

Other parents shared similar experiences including a father who discussed the process, "I didn't know that this would be ongoing, just keep finding things out, talk to the teacher, the doctor, my wife. You know, make a decision, learn about things, then try it out, just a continuous thing." Another parent shares her views on the process of seeking treatment.

The whole experience, you know, the journey from start to now, not the finish, because I don't think there really is an official finish to this, just the journey you take with your child, your spouse, you look back and see how much this really affects you and your family.

Discussion of Findings Relative to Current Literature

The findings of this study lend support to existing qualitative studies about the experiences of families who sought treatment for children with ADHD, as well as the experiences of teachers and healthcare professionals who treat and work with families of children with ADHD. Overall, there was a lack of research related to the process of

seeking treatment for families of children with ADHD. This study aimed to explore and describe the actual social processes of families who sought treatment for children with ADHD.

Earlier in this chapter themes and subthemes were identified that described the process families follow to seek treatment for children with ADHD. Within the theme of *getting started*, the subtheme of *parent suspicions* described the process that most parents in this study followed when they suspected their child had symptoms of ADHD and started seeking treatment. A study by Maniadaki, Sonuga-Barke, Kakouros, and Karaba (2006) compared beliefs of the severity, impact, and advice seeking for ADHD with parents of children whose children display ADHD behaviors compared to families whose children do not display behaviors of ADHD. Maniadaki et al. (2006) found that parents of children with ADHD behaviors tended to perceive their children as normal and did not seek treatment for their children with ADHD. This is in contrast to the findings of this study regarding the subtheme *parent suspicions* where parents did perceive their child as having ADHD and began seeking treatment. In contrast, studies by Carpenter-Song (2009) and Brinkman et al. (2009) support the theme *getting started* and subthemes of *parent suspicions* and *finding out*. Brinkman et al. described the experience of families that suspected their child had ADHD or were informed by a school professional that their child displayed symptoms of ADHD. The families in these studies began seeking treatment at that point.

In this chapter the theme *gathering information*, with the subthemes *seeking advice*, *back and forth*, and *reassurance* were identified to describe the part of the process of seeking treatment involving the actual diagnosis of the child with ADHD. Ghanizadeh and Zarei (2010) found that most primary care providers preferred not to

treat children or provide counseling to families of children with ADHD in primary care, rather they preferred to refer children to psychiatrists and psychologists. The results from Ghanizadeh and Zarei's study contradict with the results of this study, wherein most families saw a primary care provider to treat their children with ADHD and also sought reassurance from their primary care provider regarding their children with ADHD.

Ross, Chan, Harris, Goldman, and Rappaport (2011) conducted a study describing primary care physician collaboration with psychiatrists and psychologists who diagnosed children with ADHD. The researchers found that primary care providers were comfortable treating children with ADHD who were initially diagnosed by a specialist, and felt that communication between the provider and specialist was less than adequate and caused confusion between the family, specialist, and provider. The findings of this study support the findings by Ross et al. The subtheme of *back and forth* described the process of communicating with specialists, primary care providers, and school personnel, with parents describing a back and forth process between the primary care provider, specialist, and family.

The findings of this study are also supported by results of a study by Travell and Visser (2006) who found that families who sought treatment for ADHD each had unique experiences, but followed a similar process from suspicion, through seeking diagnosis, and on to treatment and management. The researchers also found that most families medicated their children and saw their primary care provider for management. The theme of *understanding* and subtheme of *medications or not* and *perspectives* describe the process families go through to determine treatment modalities, treatment provider, and the process of coming to those decisions.

The results of this study are supported by Brinkman et al. (2009) who conducted a qualitative inquiry exploring parental anxiety in making and revisiting decisions about treatment of ADHD for their child. The researchers found that parent decisions about treatment for their child with ADHD were influenced by personal emotions and child behaviors at home and at school. Many factors contributed to the decision to medicate or not medicate their child. Parents also identified that the treatment of their child with ADHD occurred on a continuum of care and involved many decisions and processes.

Hallberg, Klingberg, Reichenberg, and Moller (2008) conducted a study exploring the experiences of parents of children diagnosed with ADHD using GT as a theoretical framework. The researchers found that parents and children experience ADHD as an ongoing disorder that necessitates constant decision-making and problem solving in coordination with primary care providers, teachers, parents, and children. This supports the results of this study, which identified the process of seeking treatment for families of children with ADHD as a complex and ongoing process.

In summary, the findings of this study suggest that families follow a process when seeking treatment for their children with ADHD, and that these processes can be described and understood. Furthermore, the findings provide perspective to primary care providers on how families access care for children with ADHD, so primary care providers may better assist families with this process.

Chapter Summary

In this chapter, the findings and discussion related to the process of seeking treatment for children with ADHD were presented. Analysis of six interviews revealed four major themes. Subthemes were noted for each major theme. Analysis of the six

interviews revealed an overarching theme, four major themes, and several subthemes for each major theme. The overarching theme was *journeying to make meaning of ADHD*. Major themes included *getting started*, *gathering information*, *understanding*, and *following through*.

Chapter V

Summary, Conclusions, Limitations, and Recommendations

The purpose of this study was to explore the process of seeking treatment for families of children with ADHD. Six parents described the processes of seeking treatment for their children. A better understanding of the process families take to seek treatment for children with ADHD can lead to increased awareness in primary care healthcare providers in assisting families with this process. In this chapter, a summary of the results, conclusions, limitations of the study, with recommendations for nursing practice, education, and further research are presented.

Summary

Attention deficit hyperactivity disorder is one of the most common mental health diagnoses in children and adolescents. According to the Centers for Disease Control, Summary Health Statistics for U.S. Children (Bloom & Cohen, 2007), 4.5 million children in the United States have ADHD. Attention deficit hyperactivity disorder is a chronic condition that can significantly impact academic performance, social interaction, self-esteem, and family function. This study attempted to explore the process by which families seek treatment for their children with ADHD.

This was a qualitative study using Glazer and Strauss' (1967) Grounded Theory as a theoretical framework. Data were collected using demographic questionnaires and unstructured interviews comprising open-ended questions. A convenience sample of seven parents from a Midwestern outpatient child and adolescent mental health clinic was recruited by mail to participate in this study. One interview was a pilot interview and

was not included in the data analysis. Face-to-face interviews were held at a physical location chosen by the interviewee. The audio-taped interviews lasted approximately 30 to 45 minutes. The tapes were transcribed verbatim and analyzed using Colaizzi's (1978) method of qualitative analysis.

Analysis of data revealed four major themes. The first major theme was *getting started*, which described how the parents initiated the process of seeking treatment for their children with ADHD. *Getting started* was further broken down into the subthemes *parent suspicions* and *finding out*. The parents described the process of initiating treatment for their children as occurring through either their own suspicions about their child having ADHD or by being notified by a teacher or healthcare provider that their child may have ADHD.

The second major theme was *gathering information*, which described how parents sought diagnosis and medical treatment and counseling for their children with ADHD. Gathering information was further broken down into the subthemes *seeking advice*, *back and forth*, and *reassurance*. All parent participants noted that they followed a process of gaining information that included aspects of seeking advice from teachers, peers, and healthcare providers regarding diagnosis and treatment options. Parents also noted that there was a process of going back and forth between school professionals, healthcare professionals, and the parents themselves to gather information and communicate data needed to facilitate a diagnosis. Parents also followed a process of seeking reassurance when gathering information to help validate their intentions and keep advancing the process.

The third major theme was *understanding*, which described the process involved in understanding their child's diagnosis and options for treatment. Two subthemes were

evident within the theme understanding including *perspectives* and *medications or not?* Parents continually noted that the process of seeking treatment was impacted by understanding the different perspectives offered by school professionals and healthcare professionals regarding recommendations and suggestions for treatment and management of their child with ADHD. The parent participants also noted that a significant process was the decision to medicate their child.

The fourth major theme was *following through*, which described the ongoing process of seeking treatment for their child with ADHD after diagnosis and management were in place. The subthemes *the end is relative* and *crossing the bridge* both described processes within following through. The *end is relative* described the process parents took to gain perspective on their child's diagnosis of ADHD. *Crossing the bridge* described the process parents took to plan for their child's diagnosis in the future.

The overarching theme identified was *journeying to make meaning of ADHD*, which describes the entire process parents took to seek treatment for their children with ADHD.

Conclusions

The findings of this study uncovered processes that families follow when seeking treatment for their children with ADHD. Grounded theory seemed to be the most suitable research method for this study because the research question concerned the process of a parent seeking treatment for their child with ADHD. Grounded theory includes the belief that meaning is constructed and changed by interactions among people. Following are some conclusions from this study:

1. Families follow a social process when seeking treatment for children with ADHD. The overall theme of this process is *journeying to make meaning of ADHD*.
2. The social process of seeking treatment for children with ADHD is a complex process, and includes continuous interactions with many different individuals and occurs over time.
3. The process of seeking treatment is unique to each family, but similarities exist between families and include the themes of *getting started, gathering information, understanding, and following through*.
4. The process of seeking treatment occurs on a continuum with a definite starting point. The starting point occurs through parent intuition and/or notification from an individual who is familiar with both the child and the parent, such as a teacher or primary care provider, that the child may have ADHD.
5. Primary care providers play a significant role in the process of seeking treatment, working as a partner with the family and child to provide treatment recommendations, prescribe medications, and act as a professional resource providing support and resources to help guide the family through the process of seeking treatment.

Limitations

The study had several limitations, which are listed below.

1. Some potential problems with the use of grounded theory method can include the misinterpretation of the theory itself. Grounded theory is a method that is

not easily understood, and there are many different interpretations of GT methodology. The researcher was aware of this, and used GT only as a guide to explore a social process.

2. Possible errors in data collection and analysis: The researcher minimized the potential for such errors by performing a pilot interview and member checking, and also worked with an experienced qualitative research advisor who reviewed the work in progress and provided recommendations throughout this study.
3. The small sample size also limits the generalizability of the findings. In regard to this study, generalizability was not the primary goal; rather the researcher was looking for rich data.
4. The sample was a convenience sample, which can also be a limitation. All of the people interviewed were White, had commercial insurance, ranged in age from 33 years to 47 years, were mostly female, and had a household income between \$46K-110K. The findings may not be appropriate for others outside of these ages, insurance status, income level, gender, or race.

Implications for Nursing Practice, Education, and Administration

Nursing practice.

Understanding the social process of families seeking treatment for children with ADHD is crucial to providing timely and holistic nursing care. Given the widespread prevalence of ADHD in children and adolescents, nurses and advanced practice nurses will most likely come in contact with families who are seeking treatment for children with ADHD. The understanding of this process is imperative so that nurses and advanced

practice nurses can best provide the appropriate interventions and care at the correct time in the process appropriate to families and children seeking treatment for ADHD. Advanced practice nurses working in primary care have the ability to partner with families who are seeking treatment for their children with ADHD and provide information, support, and medication management. Advanced practice nurses working in primary care have the ability to work with families along the continuum of seeking treatment from initial diagnosis to ongoing treatment.

Assessing for ADHD in children and adolescents in the primary care environment is the first step that advanced practice nurses can implement to provide competent care for families seeking help for their children with ADHD. Advanced practice nurses working in the primary care environment should understand that the process of seeking treatment for children with ADHD is unique to each family, and families seek out help from primary care providers for diagnosis, management, and recommendations. Advanced practice nurses must be comfortable treating families and children diagnosed with ADHD, and must be knowledgeable about current research, treatment modalities, and services available to help families with the process including both community and healthcare resources. Advanced practice nurses must be comfortable acting as an advocate for the family and child, and guide them through the process of seeking treatment.

Nursing education.

Since ADHD is a widespread and common condition found in the pediatric and adolescent population, nurse educators have accountability to educate other nurses about childhood ADHD, as well as work with families who are seeking treatment for children with ADHD. Nurse educators must be cognizant of current nursing research on

this topic and encourage increased awareness through future research. Additionally, an understanding of GT is essential in understanding social processes that patients and families experience. This framework should be incorporated into the instruction of all nurse educators.

Nursing administration.

Nurse administrators must also understand the process by which families seek treatment for children with ADHD. Social, financial, and economic factors may influence the process of seeking treatment and nurse administrators are in the unique position to facilitate change that positively impact how families seek treatment for children with ADHD.

Recommendations for Further Research

Childhood ADHD continues to be a significant medical diagnosis and social concern that is increasing in prevalence. More research focusing on the process of families who seek treatment for their children is essential.

1. Quantitative tools can be used to assess families who are seeking treatment for ADHD.
2. Qualitative studies looking at family and social influences on the decision to seek treatment for children with not only ADHD, but all mental health concerns may also give healthcare providers insight into the underlying factors contributing to the family process of seeking treatment for children with ADHD.

3. Future studies should attempt to include a larger and more diverse sample with specific focus on diversity regarding ethnicity, family income, insurance type, education level of the parent, and marital status of the parent.
4. Future research should attempt to expand on individual themes identified in this study, with further study warranted related to the process of seeking treatment and focusing on the overarching theme identified in this study with the potential to develop formal theory.

Chapter Summary

A summary of the current study's findings along with a discussion of the study's limitations was presented in this chapter. Recommendations for nursing practice, nursing education, and nursing research were also presented. It is intended through this research that primary care providers will become more aware of the process families undergo when seeking treatment for children with ADHD so that they may facilitate and understand this process to better help children and families of children with ADHD. Healthcare providers must evaluate all families and children consistently for ADHD and provide the appropriate counseling, treatment, and support to these patients and families.

APPENDIX A
DATA COLLECTION INSTRUMENTS

DEMOGRAPHIC DATA

Dear Parent/Guardian: Please put an X or Circle the response where appropriate. Your answers are confidential. You will not be identified. **Please do not put your name on this form.**

Gender

Male _____ Female _____

Your relationship to the child

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

Current marital status

Single _____

Married _____

Living With Another _____

Divorced _____

Separated _____

Widowed _____

Number of adults in home

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

Age

18-25 _____

26-30 _____

31-35 _____

36-40 _____

41-45 _____

46-50 _____

51-55 _____

56-60 _____

>60 _____

What is the highest level of education you have completed?

Elementary _____

High school/Equivalent _____

Vocational/Technical School _____

Bachelor's Degree _____

Master's Degree _____

Doctoral Degree _____

Professional (MD, DO) _____

How would you classify yourself?

Caucasian/White _____

Arab _____

Latino _____

Hispanic _____

Black _____

Native American _____

Asian/Pacific Islander _____

Multi-Racial _____

Other _____

Would Rather Not Say _____

Family income

\$0-\$19,999 _____

\$20,000-\$34,999 _____

\$35,000-\$49,999 _____

\$50,000-\$64,999 _____

\$65,000-79,999 _____

> \$80,000 _____

Would Rather Not Say _____

Employment status

Employed full time _____

Employed part time _____

Unemployed _____

Disability _____

Retired _____

Which of the following best describes the area you live in

Urban _____ Suburban _____ Rural _____

Number of children in family

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

What Type of Insurance do you have (check best answer)

Commercial _____

Medicaid _____

Both _____

The following questions are about your child who has ADHD

1. What is your child's gender?

Male _____ Female _____

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

0-2 _____

3-5 _____

6-10 _____

11-14 _____

>15 _____

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

0-2 ____

3-5 ____

6-10 ____

11-14 ____

>15 ____

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

<1 year ____

1-2 years ____

3-4 years ____

>4 years ____

5. Who diagnosed your child with ADHD?

Nurse Practitioner ____

Doctor (MD/DO) ____

Therapist/Counselor ____

Psychiatrist ____

Psychologist ____

Other (Please describe) _____

6. Do you give your child medication for his/her ADHD?

Yes ____ No ____

APPENDIX B

UW OSHKOSH IRB APPROVAL LETTER



January 7, 2011

Mr. Ryan Hermus
914 W 5th St.
Appleton, WI 54914

Dr. Mr. Hermus:

On behalf of the UW Oshkosh Institutional Review Board for Protection of Human Parent participants (IRB), I am pleased to inform you that your application has been approved for the following research: The Process of Seeking Treatment: How Families Access Care for Children with ADHD.

Your research has been categorized as NON-EXEMPT, which means it is subject to compliance with federal regulations and University policy regarding the use of human parent participants as described in the IRB application material. Your protocol is approved for a period of 12 months from the date of this letter. A new application must be submitted to continue this research beyond the period of approval. In addition, you must retain all records relating to this research for at least three years after the project's completion.

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

Sincerely,

A handwritten signature in black ink, appearing to read "Frances Rauscher".

Dr. Frances Rauscher
IRB Chair

cc: Dr. Jaya Jambunathan
1931

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APPENDIX C
CONSENT FORM

Informed Consent

THE PROCESS OF SEEKING TREATMENT: HOW FAMILIES ACCESS CARE FOR CHILDREN WITH ADHD

I, Ryan Hermus, RN, BSN, Master of Nursing candidate at the University of Wisconsin Oshkosh am conducting a study to explore the process by which families seek treatment for children with Attention Deficit Hyperactivity Disorder (ADHD). I would appreciate your participation in this study as it will help my colleagues and me to better understand how families access care for their children with ADHD.

As a part of this study, you will complete two short demographic questionnaires, one about yourself and the other about your child with ADHD, in addition to participating in a personal interview. The demographic questionnaires will take approximately 15 minutes to complete and the interview will be approximately one hour in length. The interview will be audio taped and notes will be taken during the interview by this researcher.

Although there are other methods of acquiring this information, I feel that the interview serves as the best way to acquire this data because it will provide a detailed description of your experience. The study may present emotional distress as it relates to the potential sensitive nature of the information discussed. The results of this study may or may not benefit you directly, but they will help the researcher potentially provide information to the health care community on how families access care for their children with ADHD.

The information gathered in the interview and demographic sheet will be recorded anonymously. No information about you or your child will be released in any way that could identify you or your child.

If you would like to withdraw from the study at any time, you may do so without penalty. The information collected from you up to that point in time would be destroyed if you so desire.

When the study is completed I would be happy to share the results with you. Meanwhile, if you have any questions, please feel free to contact:

Ryan Hermus, RN, BSN
(920) 362-4454
hermur19@uwosh.edu

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

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

Although the chairperson may ask for your name, all complaints are kept in confidence.
I have received an explanation of the study and agree to participate. I understand my participation in this study is completely voluntary.

Name

Date

I agree to allow audio taping of the interview for information collection.

Name

Date

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