Information and Advice Parents of Children with ADHD Want From Their Primary Care Provider

By

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ABSTRACT

TITLE: Information and Advice Parents of Children with ADHD Want From Their Primary Care Provider

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The purpose of this exploratory study was to identify the type of information and advice parents of children with ADHD (attention deficit hyperactivity disorder) want from their child's primary care provider. Primary care providers serve as sources of information about parenting as well as how to manage acute and chronic conditions in childhood. ADHD is a chronic condition that is manifested by some combination of inattention, distractibility, impulsivity, and hyperactivity. Stimulant medication is available to mitigate these behaviors but the effects of the disorder on family members are associated with increased stress and decreased family functioning.

A convenience sample of 35 parents of 33 children who attended local chapter meetings of a national parent support group for ADHD was used. A survey containing 64 items about behaviors related to activities of daily living, diagnostic features of ADHD, and parenting concerns was used for data collection. Parents indicated if the item represented a problem for them and rated the magnitude of the problem using a Likert-type scale of 0-10. Four open-ended questions asked what advice from primary care providers was helpful, unhelpful, desired but not received, and what parents wanted their primary care provider to know about ADHD and families.

Results from the quantitative data indicate parents in this study rated parenting activities related to managing routines, school, behavior and socialization more

problematic than managing concerns about eating, sleeping and dressing, and they wanted advice regarding these issues from their primary care provider. Those parents who indicated that medication management was a problem rated it as a "big" problem. Findings from the qualitative data indicated parents of children with ADHD wanted information and advice specific to ADHD to empower them to fulfill their parenting role and they wanted information about the diagnosis and prognosis of ADHD. In addition, they wanted care and support from their primary care provider, as demonstrated by an understanding of how ADHD affects the entire family and by referrals to appropriate resources in the community.

Further studies are needed to refine the survey instrument and strengthen its psychometric properties with random sampling among diverse regional, socioeconomic and ethnic groups. There is a need to explore concerns of parents diagnosed with ADHD themselves and how that impacts their parenting. Studies are needed to identify effective parent education and training methods that are adaptable to clinical and research settings, and to understand how ADHD affects the family.

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Chapter 1

Introduction

Attention deficit hyperactivity disorder (ADHD) is the most commonly diagnosed mental health problem in childhood. It is estimated to affect 3 to 9% of all children (Barkley, 1990). The primary features of this disorder are inattention, impulsivity and overactivity. Children can be affected by one, two or all three of the features. These primary behaviors and their secondary manifestations can affect every aspect of life for these children and their families.

The chronic nature of ADHD and its impact on parenting and family function gives rise to families turning to health care professionals for advice about parenting in this special context (Murphy & Hagerman, 1992). There is a need to learn more about the kinds of advice these parents most need and want.

Statement of the Problem

Attention deficit hyperactivity disorder is a complex diagnosis and multimodal treatment is indicated. Multidisciplinary teams agree that, in addition to prescribing stimulant medication, other important therapies include family education, cognitive and behavioral therapy, behavior modification and psychosocial counseling (Nathan, 1992). Nurses with basic skills as well as those prepared for advanced practice can contribute significantly to most of these areas of intervention (Cantwell & Baker, 1987; Diacon, 1992; Gregory, 1993).

The purpose of this study was to identify what kinds of advice about parenting and managing daily living parents of ADHD children want from their health care

providers. This is especially relevant to nursing as more nurse practitioners assume primary care responsibilities for families and as the emphasis in health care delivery shifts to health promotion and community-based programs, away from acute care in hospital-based settings (Spellbring, 1991). In addition, many mental health problems are being managed by primary care providers instead of mental health providers as a cost containment measure (Cantwell & Baker, 1987).

In my primary care practice as a pediatric nurse practitioner I have discovered that advice for parents based on generic child development principles in not enough. There also is a need for specific information that applies to raising a child with ADHD.

Chapter 2

Background

The nature and complexity of attention deficit hyperactivity disorder (ADHD) have been observed over time. While the behaviors associated with attentional difficulties still reflect the picture first described at the turn of this century, defining characteristics of the disorder have changed over time (Barkley, 1990). Four editions of the Diagnostic Statistical Manual of Mental Disorders published during the last 25 years have included markedly different criteria for the diagnosis of attention deficit hyperactivity disorder as scholars and clinicians have tried to tease out the essence of attentional problems and differentiate it from other diagnostic categories. ADHD has been called the hyperkinetic syndrome, minimal brain dysfunction and attention deficit disorder prior to the most recent DSM-IV (APA, 1994) edition. This has led to confusion for practitioners trying to make accurate diagnoses, and for parents, schools, and even the children themselves who are trying to live with and mitigate the consequences of the associated behaviors.

Other changes during the last half century have impacted families of children with attention deficit hyperactivity disorder. Roles within the family are more diverse today when compared to mid-century expectations (Duvall & Miller, 1985). Many parents today perceive themselves insufficiently educated about raising children and seek help from professionals with their role as parent (Campbell, 1992). The idea that parenting is a learned skill instead of an intrinsic ability underlies many programs in parent education (Reuter, 1988). Nurse practitioners, pediatricians and other primary care providers have

included anticipatory guidance as part of routine well child care during the last few decades; health care providers now are perceived as a primary resource for parent education (Christophersen, 1992).

There is a growing body of knowledge about how parenting and family functioning are affected when a child has a chronic disease or disability, and how these two variables impact the child's experience of illness. Nursing as a profession has taken an active role in researching this area (Gallo, 1991; Holoday, 1984, Lewis, 1992; Lewis-Abney, 1993).

Review of Related Literature

The review of literature was focused in the following areas: ADHD diagnosis and treatment, the chronicity of the disorder and its effects on families, and parenting and managing daily living activities of ADHD children. The following is a summary of that review.

ADHD

An overview of attention deficit hyperactivity disorder literature provides a definition of the medical problem and current recommendations for treatment. Barkley's text (1990) is a classic work which was recently revised. It contains a detailed history of the disorder, extensive diagnostic criteria, differential diagnoses and six chapters devoted to assessment. The latter half of the book discusses treatment of the child and family as a system and recommends parent counseling and parent training programs.

Levine (1992) described components of attention, distractibility and impulsivity. Attention includes an ability to maintain concentration for an appropriate period of time

and to resist attending to competing stimuli that occur simultaneously (Levine, 1992). Without these abilities children and adolescents appear distracted and very creative at times when the expectation is that they will and should concentrate on something else. Attention also implies skill at picking out salient vs. trivial information and choosing effective problem-solving strategies. Lacking this component of attention leads to "missing the point" in academic and social situations, and "doing things the hard way" without careful thought about how to plan and solve a problem.

Distractibility is a by-product of inattention that results when one pays attention to multiple stimuli at one time or in rapid succession (Levine, 1992). Related to distractibility is the difficulty in maintaining enough mental effort to complete a task. These characteristics lead to inconsistent performance in school and often loss of interest in activities and social plans.

Impulsivity is described in the Diagnostic Statistical Manual-IV (APA, 1994) in part by its manifest behaviors. Impatience, difficulty delaying responses, including blurting out answers in class or interrupting conversations, and blundering without following directions are examples of impulsivity, representing acting before thinking.

Hyperactivity describes the cluster of behaviors of overactivity, including fidgeting, an inability to remain seated when expected, and moving "as though driven" (APA, 1994). Not only do these behaviors interfere with attention but they also are regarded as disruptive to group activities and create negative social consequences.

Nursing articles about ADHD are relatively few and limited in scope. Most focused on diagnostic criteria and described the nurse's role in administering medication

(Diacon, 1992; Gregory, 1993; Murphy & Hagerman, 1992). One nurse researcher described the effects of ADHD on family functioning (Lewis, 1992; Lewis-Abney, 1993).

Chronic Illness

The second area of the literature review includes a description of chronic illness in children and its impact on the children and their families. Seligman and Darling (1989) used a systems approach to describe childhood chronic illness and disability. Their comprehensive search of the literature revealed that the following characteristics of childhood chronic illness influence how parents go about raising a child with a chronic illness or disability: specialized medical care needs, special education needs, behavior problems associated with illness and disabilities, and continuing dependence on parents instead of progressive independence.

Initially it was though that children outgrew the symptoms of attention deficit hyperactivity disorder during adolescence (Barkley, 1990). There is general consensus now that ADHD is a chronic disorder and the symptoms that were problematic in school affect occupational performance (Barkley, 1990; Cantwell & Baker, 1987; Varley, 1984).

Several characteristics of chronic illness identified previously by Seligman and Darling (1989) were examined in a nursing study by Lewis-Abney (1993) who found that age of the child and the severity of ADHD symptoms correlated with the level of family functioning. Two questions about families with an ADHD child were investigated: 1) Was there a relationship between demographic and psycho-social family characteristics and family functioning, and 2) which combination of demographic and psycho-social family characteristics best predicted family functioning? A convenience sample of 123

parents of 79 boys ages 6-11 were asked to complete three questionnaires about family adaptability and cohesion, child behaviors related to ADHD and family demographics. Correlations and multiple regression analyses were calculated; results indicated that parents of older children reported lower levels of family functioning. It was felt that this was not causal, but instead due to cumulative negative effects over time. Lewis-Abney recommended that teaching parents more effective communication skills is one direct nursing intervention that can improve family functioning.

Parenting and Managing Daily Living

Ross and Ross (as cited by Lewis-Abney, 1993) suggest that ADHD children exert a more powerful effect and can produce more tension in their families than do normal children. In a pediatric journal issue devoted to development and behavior in older children and adolescents, Kelly and Aylward (1992) identified general home management interventions that aim to modify daily routines to promote success for the ADHD child and to mitigate or change dysfunctional patterns of behavior that might have developed before diagnosis and treatment of ADHD began.

Anastopoulos and colleagues (1993) described a parent training program developed by Barkley (1990) specifically for parents of ADHD children. A convenience sample of mothers of 36 children between 6 and 11 years of age who were referred to a university medical center ADHD clinic participated in a 2-month parent training program. Subjects were assigned to either the parenting training group or a waiting list for the parent training program. Those assigned to the waiting list served as a control group and were given the parent training when the study ended. Diagnosis was verified using the

Barkley (1990) semistructured psychiatric interview and ADHD child behavior checklists. Mothers attended eight sessions that provided education about the disorder, positive reinforcement skills for desired child behaviors, punishment strategies and handling misbehavior in public. Outcomes measured were parenting stress, parents' sense of competence, parents' personal distress, marital adjustment, and knowledge of ADHD. Chi square and t-test analyses were made to compare the parent training group and the waiting list group. Parents reported improvement in the overall severity of ADHD behaviors, increased parent functioning and a reduction in parent stress. The improvement lasted over a 2 month period when no follow-up was provided.

No studies were found in which parents' statement of need or requests for particular advice were used as the basis for content of parent training programs. This is significant when compared with numerous books available to parents of children with ADHD in two large national mail order catalogs (ADD Warehouse Catalog, 1994; Sun-America Catalog, 1994).

Conceptual Framework

Family systems theory supports the idea that a diagnosis of attention deficit hyperactivity disorder in one family member will affect the entire family (Lewis-Abney, 1993). Because of the multi-dimensional and intrusive nature of this diagnosis, one assumes a significant impact on a family and the performance and unfolding of parental and child roles within a family.

The problems parents of ADHD children report can be organized into two main areas: activities of daily living (eating, sleeping, dressing, etc.) and management of

behavior related to ADHD (inattention, impulsivity, hyperactivity). These concepts were derived from the researcher's clinical practice and extracted from the lay literature.

An assumption underlying this study is that parents know what advice specifically related to ADHD they want and need from health care providers and that parents can articulate this when asked.

Research Question

The research question is: What advice about parenting and managing daily living do parents of a child with ADHD want from their primary care providers? The question builds on the knowledge that attention deficit hyperactivity disorder affects the entire family system, that many parents today seek help with the parenting role, and that primary care providers can serve as an effective resource for parents when they know what information and advice parents want and need.

Chapter 3

Methods

This study used an exploratory design to answer the question: what information and advice about parenting and managing daily living do parents of ADHD children want from the health care providers? The need to begin to identify specific content areas guided the choice for an exploratory design. A survey using a self-report questionnaire with both quantitative and qualitative components was used to collect data from a sample of parents of a child with ADHD.

Sample

A convenience sample of 35 parents of children diagnosed with ADHD participated in the study. Parents attending local chapter meetings of a national ADHD parent support group were invited to participate. Parents who attended these meetings were referred to the support group by their health care provider, school personnel, or other parents who have a child with ADHD. In this area, newspapers carry notices of monthly meetings, HMO (Health Maintenance Organizations) newsletters advertise the meetings and a large monthly mailing is undertaken by support group leaders. Inclusion criteria required that participants be English-speaking, be able to read and write in English, and have at least one child diagnosed with ADHD.

Data Collection Procedures

Seventy-five questionnaires were distributed at meetings of five parent support groups. Participants were encouraged to complete the survey during the meeting, but self-addressed envelopes were available for those who chose to return it by mail. The

researcher was present to introduce the study, explained voluntary, anonymous participation, distributed the questionnaires and remained available while participants competed the survey.

Instruments

A questionnaire was developed using guidelines by Fowler (1984) to identify types of advice about parenting and daily living that parents of ADHD might want from their primary health care provider. A combination of closed-ended and open-ended questions were written to reflect parenting concerns identified from the literature and from the experience of the researcher's clinical practice. Sixty-four items were grouped into 9 categories: Four categories related to diagnostic features of ADHD, 3 categories related to activities of daily living, 1 category related to medication, and 1 category related to parenting concerns. Participants were asked to indicate if they would like information or advice about each item and to rate the magnitude of the problem by using a 0-10 point Likert-type scale with 0 indicating "no problem" to 10 indicating a "big problem". Four short open-ended questions were asked: 1) What advice have you received from your primary care provider that was helpful? 2) What advice would you have liked to receive (but did not get) from your primary care provider? 3) What advice did you get from your primary care provider that was not helpful? 4) What things do you want your primary care provider to know about attention deficit hyperactivity disorder and how it affects families? The following demographic information was also requested: gender, age, educational level, marital status and personal history of an ADHD diagnosis for the parent; age, gender, grade level, number of sibs with and without ADHD, and

medication status for the child with ADHD. The questionnaire was reviewed by an expert who diagnoses and treats ADHD children and a piloting of the questionnaire was made with four parents before it was used in this study.

Reliability and Validity of the Instrument

Alpha coefficients was used to estimate reliability of the survey. Scores for the subscales ranged from .74 to .94. Content validity was assessed by two experts in the field and by comparing items contained in the survey with the scope of topics included in the lay literature about educating parents of children with ADHD.

Protection of Human Subjects

The proposed study was submitted for review for the protection of human subjects and approved according to the guidelines provided by Oregon Health Sciences University. Informed consent was implied by voluntary participation after the researcher explained the purposes and procedures used in the study. Confidentiality was assured by asking participants to complete the survey anonymously.

Sample Characteristics

The characteristics of the parents, families and children represented in this study are described below and summarized in Tables 1 and 2.

Characteristics of the Parents

There were thirty-five parents of 33 children diagnosed with ADHD who participated in the study; 27 (79%) were mothers of children with ADHD and 7 (21%) were fathers. The average age of the parents was 40.5 years (SD 7.10 years) with a range of 26 to 52 years of age.

Table 1
Characteristics of the Children Represented in the Sample

	N	%
Gender		
Male	31	89
Female	4	11
Grade		
Preschool or Kindergarten	5	15
Elementary	20	60
First	2	6
Second	4	12
Third	5	15
Fourth	6	18
Fifth	1	3
Sixth	2	6
Middle and High School	9	27
Seventh	4	12
Eighth	3	9
Ninth	1	3
Tenth	1	3
Does your child have an Individualized Educational Plan (EIP)		
Yes	17	50
No	17	50
Is your child taking medication for ADHD?		
Yes	24	69
No	11	31
What type of medication does your child take for ADHD?		
Ritalin only	15	63
Other ADHD medications only	2	8
Two or more ADHD medications	7	29
Does your child understand his/her ADHD?		
Yes	14	41
No	11	32
Missing data	10	27
What kind of primary care provider does your child see?		
Pediatrician	28	80
Family practice physician	6	17
Nurse practitioner	0	0
Physician's assistant	1	3

Table 2
Characteristics of the Parents and Families in the Sample

	N	%
Parent participant		
Mother	27	79
Father	7	21
Marital status of parent participation		
Single	3	8
Married	28	80
Widowed	2	6
Divorced	2	6
Education level of parent participant		
1-2 years college	12	43
3-4 years college	10	36
5-6 years college with MS/MA	6	21
Number of children in family		
1	5	14
2	16	46
3	9	26
4	4	11
5	1	3
Number of children with ADHD in family		
1	26	74
2	9	26
Number of custodial parents diagnosed with ADHD		
One parent	7	20
Both parents	0	0
Neither parent	28	80
Number of non-custodial parents diagnosed with ADHD		
One parent	6	19
Number of extended family members diagnosed with ADHD		
At least one	20	61
Relationship of extended family member with ADHD to child with ADHD		
Father	6	31
Brother	1	5
Uncle	4	21
Cousin (gender unspecified)	2	11
Mother	1	5
Aunt	1	5

All parents reported they had finished high school. A majority of parents (80%) completed a vocational training program or a college degree. Twelve (43%) parents had a vocational training certificate or an associate degree; 10 (36%) parents completed 3 to 4 years of college, and 6 (21%) had a master's degree.

The majority of parents (80%) were married. Three parents (8%) were single, 2 (6%) were widowed, and 2 (6%) were divorced. Seven parents (20%) reported they had been diagnosed with adult attention deficit hyperactivity disorder.

Characteristics of the Families

Five families (14%) had one child, 16 families (46%) had two children, 9 families (26%) had 3 children and 5 families (14%) had 4 or more children. Twenty-six families (74%) had one child diagnosed with ADHD; 9 families (26%) reported having 2 children with ADHD. Regarding biological but non-custodial parents (who did not themselves participate in this study), 6 (19%) were reported to be diagnosed with ADHD.

Twenty families (61%) indicated that at least one member in the nuclear or extended family had ADHD in addition to the child described in the study: Six (31%) were fathers; 1 (5%) was a brother, 4 (21%) were uncles, and 2 (11%)were cousins with gender unreported. Three family relatives with ADHD were female: One (5%) was a mother, 1 (5%) a sister and 1 (5%) an aunt. Three (16%) additional family members were reported to have ADHD but the relationship to the child was not described.

Characteristics of the Child

Thirty-one (89%) of the children in this study were male, 4 (11%) were female. Five (15%) of the children were in preschool or kindergarten, 20 (60%) were in elementary school and 9 (27%) were in middle or high school (percentages add up to more than 100% because of rounding). Seventeen (50%) of the children had an individualized educational plan (IEP); 17 (50%) children did not.

Regarding medication for ADHD, 24 children (69%) used medication and 11 (31%) did not. Fifteen children (63%) used Ritalin, 2 children (8%) used another stimulant-type medication. Seven children (29%) were taking a combination of 2 or more medications related to the diagnosis of ADHD.

The majority of children (80%) received their health care from a pediatrician, 6 children (17%) were seen by a family physician and one child (3%) received health care from a physician's assistant (PA).

Chapter 4

Results

The purpose of this study was to identify what kinds of advice about parenting and managing daily living parents of children with ADHD want from their health care providers. Descriptive statistics were used to analyze the quantitative data using recommendations by Fowler (1984). Results are presented in two ways: Group means and standard deviations for survey categories appear in Table 3, and twenty individual survey items rated as most problematic as indicated by individual item mean scores are found in Table 4 in descending order. Means and standard deviations for all survey items are listed in Appendix A.

Qualitative data were analyzed and summarized according to content categories. Results from the qualitative analysis provided clarification and illustration to the findings of the quantitative data (Miles and Huberman, 1994).

Table 3
Group Means and Standard Deviations

Survey category	N	Mean	SD
Routines (R)	35	7.09	2.04
School (SC)	34	6.84	2.65
Behavior (B)	35	6.32	2.18
Socialization (SO	35	6.11	2.71
Eating (E)	35	4.76	2.12
Parenting (P)	35	4.72	3.42
Medication (M)	35	4.65	2.96
Sleeping (S)	35	4.23	2.37
Dressing (D)	35	3.68	2.63

Table 4
"Twenty Most Problematic" Individual Survey Items

Item	Mean	SD	Rank	Categ.
Picking up after himself or herself.	8.57	1.85	1	R
Managing resistance or refusal to follow routines	8.06	2.30	2	R
Getting my child to write down & bring home assignments, books, etc.	7.77	3.20	3	SC
Getting my child to do homework	7.70	2.98	4	SC
Getting my child to complete his chores on time	7.57	2.65	5	R
Dealing with hitting, throwing or breaking things in anger	7.43	3.20	6	B
Stop interrupting while I am talking with others.	7.40	2.99	7	SO
Stop interrupting while I am talking with others.	7.23	3.17	8	SO
Stop interrupting while I am on the phone.	7.14	3.14	9	SO
Getting my child awake and going in the morning	7.11	3.13	10	SL
Managing when special events interrupt daily routines	7.06	2.98	11	R
Getting my child to stop losing or failing to turn in completed homework	7.03	3.58	12	SC
Knowing what is realistic for an after school routine	7.03	2.64	13	R
Setting limits for verbal abuse: name calling, cursing, etc.	7.03	3.42	14	B
Get along without fighting other children.	6.91	3.19	15	SO
Decreasing my child's behavior problems at school.	6.78	3.49	16	SC
How to get my child to fall asleep more easily.	6.57	3.58	17	SL
Preventing or managing outbursts in public	6.57	3.40	18	B
Knowing what is realistic for a morning routine	6.51	2.98	19	R
Understanding how my child's medication works and why it is needed.	6.23	3.87	20	M

Quantitative Data

Results from analyzing group means and standard deviations and from examining individual items according to "amount of problem" indicate parents have a greater need for information and advice about behavioral manifestations of ADHD (survey categories called routines, behaviors, school and socialization). Parents did not indicate the same "amount of problem", and by inference, need for general advice, about managing activities of daily living which are influenced by family style and personality as well as ADHD characteristics (survey categories called eating, sleeping and dressing).

In four categories group means were above 5.0 and individual items from those categories were ranked among the "top twenty" items indicating the greatest amount of problem to parents. The category called "Routines" had the highest group mean (M=7.09) and lowest group standard deviation (SD=2.04). Six of the 8 individual items from this category are ranked within the top twenty items of greatest amount of problem; a seventh item ranked 21st and the eighth item in this category was ranked twenty-seventh among 64 total items. The category called "School" (M=6.84, SD = 2.65) contributed 4 individual items in the "top twenty most problematic items"; 3 individual items ranked as very problematic were from the category called "Behaviors" (M=6.32, SD = 2.18). The last category with a mean over 5.0 was called "Socialization" (M=6.11, SD=2.71) and contributed 4 individual items to the list of the "top twenty" most problematic items.

Five categories had group means below 5.0. The one item within the "Eating" category (M=4.76, SD=2.12) that was highly problematic for many parents was getting

the child with ADHD to eat the right foods (individual item M=5.62, SD=2.58) ranked 30th among the most problematic items. "Medications" as a category had a group mean of 4.65 (SD=2.96) but two items within the group had individual means above 6.0. Parents indicated they wanted information to understand how the child's medication worked and why it was needed (ranked 20th of 64), and information about what side effects to look for and how to manage them (ranked 24th of 64 individual items). The category called "Sleeping" (M=4.23, SD=2.37) contributed two items to those ranked as 10th and 17th. Categories called "Parenting" (M=4.72, SD=3.42) and "Dressing" (M=3.68, SD=2.63) contained individual items that were less problematic.

Using means and standard deviations alone do not fully describe the data in the two categories with the most variation as indicated by group standard deviations. Table 5 displays a frequency distribution of items within the categories called Medication and Parenting. Group means for these two categories are the lowest of the nine categories; however, findings indicate that parents who do indicate individual items in the two categories as problematic also identify them as "big problems".

Table 5.
Frequency and Percentages for "Amount of Problem"

	No problem	. . . .		Big problem
	0	1-3	4-7	8-10
Medications: 24 Children are on Medication, 11 are not (M = 2.65; SD = 2.96)				
Understanding how medication works and why it is needed	6 (.17)	4 (.11)	8 (.23)	17 (.49)
How to give medication, and when	8 (.23)	11 (.31)	6 (.17)	10 (.29)
Knowing what side effects to look for, and how to manage them	7 (.20)	1 (.03)	10 (.29)	17 (.49)
Knowing what to tell people about why my child uses medication	7 (.20)	5 (.14)	6 (.17)	17 (.49)
Working out my concerns and using "stimulant" medication	6 (.17)	7 (.20)	9 (.26)	13 (.37)
Getting school to give my child's medication on time or at all	13 (.37)	6 (.17)	5 (.14)	11 (.31)
Getting the physician forms for medication signed and to the school	15 (.44)	9 (.26)	5 (.15)	5 (.15)
Getting pharmacy to give second labeled bottle	16 (.46)	8 (.23)	7 (.20)	5 (.15)
Parenting (M = 4.72; SD = 3.42)				
Making a plan both parents can agree on how to handle discipline	7 (.20)	7 (.20)	7 (.20)	14 (.40)
How to tell people about my child's ADHD	7 (.20)	7 (.20)	7 (.20)	14 (.40)
My concerns that I might have ADHD or if I gave it to my child	16 (.46)	5 (.15)	4 (.11)	10 (.29)

Qualitative Data

Data from the four open-ended questions were analyzed for content. Three themes emerged from responses to question one, describing helpful advice that parents did receive from their primary care provider: 1) provision of education, 2) the provision of support and care, and 3) medication management. Twenty-six parents offered comments about helpful advice. Nine parents listed examples of education as helpful advice, including classes about ADHD, handouts about the diagnosis, medication, home management and behavior modification techniques, and resources. One parent described the ADHD class offered by the provider's HMO as "worth the time and money", while another mentioned that "an overview of ADHD, what it is, some behavioral techniques and complete accurate testing services and report" were helpful.

Helpful advice in the form of provision of support and care was mentioned by nine parents. The support and care came from the primary care provider himself when, as one parent stated, "Mostly he listened and showed concern, understanding and empathy." Seven parents indicated that support and care was offered when the primary care provider made referrals to other professionals who were knowledgeable about ADHD.

Medication management was the third theme identified as "helpful advice". Four parents reported they needed and received information and advice about the variety of medications available, dosage and side effects. One parent wrote about their child's primary care provider, "(He) would be conservative in prescribing medication--requiring us to come to class and learn more and we appreciate this care and not just prescribing medication carelessly."

In contrast to the comments about behaviors and actions perceived as helpful, 10 statements indicated parents received no help at all from their primary care provider nor did they receive a referral. In response to the question asking what help had been given by the primary care provider, one mother reported:

"Absolutely none-he gave me an RX for Rilatin (sic), told me it would solve all my problems (with my daughter) and said he was really busy-good-bye. I was in tears, frustrated and have called to get him to give me a referral for a second opinion and got a cold response: that he'd submit it before a review committee and call me next!"

The second open-ended question asked what information or advice parents would have liked to receive but did not get from their primary care provider. Responses indicate that parents wanted information about the diagnosis and management of ADHD and information about resources and referrals. Twenty-six parents responded to this question.

Four parents expressed concern that their child did not get an adequate diagnostic workup; others would have liked information about medication and other treatment options. One father requested "more advice on treatment besides just giving him Ritalin, the multi-modal treatment and what else is out there to help us, like the CHADD (Children and Adults with Attention Deficit Disorders) organization, classes, etc.". A mother restated similar concerns: "(He) did not receive any information on dealing the behavior issues or any information on support groups. We were just given a prescription. I would have liked more information on ADHD, i.e., books, groups, behavior management classes".

Requests for information and advice about resources and referrals were mentioned by 7 parents who specifically would have liked information about the CHADD (national support group with local chapters) and COPE (Coalition in Oregon for Parent Education), the Internet address for ADHD bulletin boards and web pages, and local classes and counselors who offer education about ADHD. One parent, recognizing the complexity of ADHD, her own needs and the demand on primary care providers, described the solution that worked for her family: "... (It would) probably helpful to have primary care providers knowledgeable about all these aspects (behaviors, meds, school issues, etc.) but not sure it's possible or practical. We use our primary care provider for meds and she coordinates with a psychologist who seems to know more about appropriate meds and school and behavior issues."

The third open-ended question asked parents what advice they received from their primary care provider that was not helpful. One parent summarized the sentiments of most of the comments offered by 18 parents by calling the unwanted advice "the brush-off". Other examples of the "unhelpful" information and advice included:

"He looked at her for 5 minutes and said she didn't have it (ADHD). I don't know how he could tell if she was in 5 minutes."

"One doctor said that because a child could sit still for 5 minutes, that she did not have ADHD."

Another physician was reported to say, "He'll be fine as soon as he learns to read."

"(Our doctor told me) that my son was just behaving like a brat and that I was expecting miracles when I told him the Ritalin was not doing what it had done for my son the previous year."

"Overload your life with sports and lessons and meetings: 'keep the kid busy and you won't notice his acting up'."

"He is just being a boy" and said we had ineffective parenting techniques."

The fourth open-ended question asked parents to indicate what they wanted their primary care provider to know about ADHD and how ADHD affects families. Three themes emerged from comments provided by 21 parents: 1) competency in diagnosing and treatment ADHD, 2) compassion, knowledge and understanding of the effects ADHD has on the entire family, and, because of that understanding and compassion, 3) ability to provide information about the stress and parenting of a child with ADHD. Results indicated that parents wanted their primary care providers to be competent and knowledgeable about the diagnosis and treatment of ADHD or to refer them to someone who is competent. One mother "would like for providers to admit when they lack knowledge themselves and refer. Too many diagnose and treat ADHD without adequate training". One parent mentioned comorbidity "and that in a lot of cases depression goes with it (ADHD)", while another mother wanted her primary care provider to know about "associated behaviors". One mother reported her primary care provider "seems to have the opinion that ADHD comes from fetal alcohol or abuse and environment rather than heredity."

Parents wanted their physicians to understand that ADHD has a profound effect on the family and wanted to be treated with compassion. One mother wrote, "The whole family needs to be 'treated' when a child is diagnosed as ADHD". Other parents wanted providers to understand "that usually there are other family members with ADHD', and that "siblings hurt and hate and that parents feel alone in it". One parent stated that "unless you have lived with this, how can you judge?" A mother wanted her physician "to know that my son is not a 'brat'; he is not behaving this way because he wants to. We don't expect Ritalin to be a cure-all, but give the family some idea of what to expect, what we also should do beside medication. I also want him to be more supportive of the kind of job we as parents are doing.".

The third theme parents expressed about what they wanted primary care providers to know about ADHD and how it affects families is a logical extension to the compassion and understanding expressed in the second theme. Given that ADHD affects the entire family, information and advice about managing the impact on families are needed and wanted. Four parents mentioned family stress as a consequence to an ADHD diagnosis. "The stress in the family can be overwhelming, especially for single parent families. Provide information and support to all members of the family, not just drugs to the ADHD child." One mother requested "some knowledge and some advice for stressed parents: recommendation of support groups and resources". Another mother described "the ongoing day to day stress" and requested "behavior management techniques addressing different parenting styles and inconsistencies". One parent reported "We don't expect Ritalin to be a cure-all but give the family some idea of what to expect, what

we also should do besides medication ... to be informed of all the things such as classes, support, groups, etc. that are available to parents and let parents know about them".

Discussion

This study proposed to discover what information and advice parents of a child with ADHD wanted from their primary care provider. Results of the study are discussed in light of this question. In addition, issues regarding methodology, clinical implications and research implications also are discussed.

The survey results indicated that problems for which parents of ADHD children requested advice can be organized into two main areas: management of inattentive, impulsive and hyperactive behaviors related to ADHD (survey categories about routines, behaviors, socialization, school and parenting), and activities of daily living (survey categories about eating, sleeping, and dressing). Findings of this study revealed that parents perceived managing routines, school, behaviors, socialization as more problematic than managing activities of daily living. It is interesting to note that many of these individual items reflect diagnostic criteria for ADHD as set forth in the DSM-IV (APA, 1994). In addition, group category labels (routines, school, behaviors, and socialization) frequently are topics of entire chapters in lay books about parenting a child with ADHD (Hartmann, 1993; McCarney & Bauer, 1990; Parker, 1988; Quinn & Stern, 1993, 1991; Serfontein, 1990).

Until recently, professional literature contained little addressing the management of problems relating to routines, school, behavior and socialization. The current trend to study program outcomes is beginning to generate knowledge about management

programs and techniques that have demonstrated success (Anastopoulous, et al., 1993; Pisterman, et al., 1992). This present study suggests that primary care providers need to educate themselves about these specific, ADHD-related management issues, and identify persons in the community to whom families might be referred.

The qualitative data added to and elaborated on the findings from the survey. Parents who participated in this study indicated that information and advice they perceived as helpful and desirable included information about the diagnosis and prognosis of ADHD (which were not addressed in the quantitative survey), management of medication, school and behavioral concerns, and resources and referrals available to the family. Although the research question focused on advice parents wanted (the word chosen by parents participating in the pilot study), the qualitative questions allowed parents to state they also wanted information. These findings were congruent with the quantitative findings except for the absence of survey items about diagnosis and treatment information. However, given the opportunity to use their own words, parents also indicated they sought support and care from their primary care provider as demonstrated by the professional's compassionate behaviors and understanding the effects of ADHD on the family, and being able to provide information about stress management specifically related the effects of ADHD.

Parents wanted information about the diagnosis and prognosis of ADHD, which was interpreted here as a request by parents "to be educated about" ADHD. This information, they believed, would enhance their ability to perform their daily and varied parenting activities. This is in contrast to the notion in the literature about parent

"training", in which parents are taught ways to "manage" specific behavioral situations (Anastopoulos, Shelton, DuPaul, & Guevremont, 1993; Pisterman, et al., 1992; Pollard, Ward, & Barkley, 1984). It is noteworthy that in articles about clinical management of ADHD, "educating" parents about the diagnosis and prognosis of ADHD was not mentioned (Cantwell & Baker, 1987; Hesterly, 1986; Murphy & Hagerman, 1992; Nathan, 1992; Odom, Herrick, Holman, Crowe & Clements, 1994). One study describing the selection of children with ADHD who might be managed in a private practice setting employed a teaching videotape for parents that did include information about diagnosis and prognosis (Waldrop, 1994). While acknowledging the different emphases reflected in clinical and research literature, parent "training" should not be a substitute for parent education nor should behavior modification programs offered to parents of children with ADHD be approached with paternalism. Parent education and parent training are different but complementary vehicles for empowering parents to take control of their own lives.

Parents in this study indicated that, in addition to information about managing behaviors related to the child with ADHD, they wanted to shift the emphasis from the child alone to a focus on the family and recognition for the attendant family stress associated with ADHD. The idea that parent training might increase parent functioning, and, therefore, reduce parent stress, was tested and found significant in a study done by Anastopoulos and colleagues (1993). The improvement in parent functioning, decreased parental stress and reported decrease in ADHD symptomatology was documented, but the mechanisms by which these occurred remained unclear. Studies show that family stress

and family functioning appear to be related when a child is diagnosed with ADHD, but the nature of the relationship or causality between diagnosis, family stress and functioning has not yet been identified (Anastopoulos, et al., 1992; Barkley, et al, 1992; Breen, 1988; Lewis, 1992; Lewis-Abney, 1993).

Sample Characteristics

Parents participating in this study represent a sample that was well educated, had reasonable access to health care and were motivated enough to seek help and support at local parent support groups. This level of motivation to seek information and support has been described in parents of children with other chronic conditions (Hartman, Radin & McConnell, 1992; Leff & Walizer, 1992). The characteristics of this sample may not be representative of all ADHD parents and, therefore, limit generalizability of these findings.

The fact that the majority of respondents were mothers (79%) who were married (80%) is also consistent with findings in other studies about parents of children with chronic conditions (McCready, 1991). Of the parents who completed the survey, 7 custodial parents (20%) reported they themselves have been diagnosed with ADHD. It is unknown whether a parent diagnosed with ADHD is more or less likely to seek information and support from a parent support group.

The parent support group proved to be a good source for locating study participants but not necessarily a good place to conduct a survey even when it was part of the evening's agenda. Distractions from children present and other speakers made it difficult for some participants, especially parents who have ADHD themselves, to complete the questionnaire at the meeting. Data collection procedures included no

provision for telephone follow-up with parents who opted to return the survey by mail. This omission has implications for clinical and research activities since distractibility, a primary feature of ADHD, affects compliance in children and parents (Anastopoulos, et al., 1992).

Clinical and Research Implications

This study grew out of concerns I had in my practice as a pediatric nurse practitioner in which I discovered that general child development information and advice for parents of a child with ADHD was inadequate. Even though results of this study are a beginning in our understanding of what parents want and need, it is useful for clinicians to listen to parents' perceptions of need for information and advice. Primary care providers have been regarded as a resource for parent education (Christophersen, 1992) and, when they are well informed, they can be particularly instrumental in providing information and advice about parenting as it relates to a medical condition. Waldrop (1994) described a system of triage for selecting children with ADHD to be managed in a private office setting. Primary care providers can manage this population successfully when equipped with advanced training in the unique complexities of this disorder and a willingness to learn from and with families of children with ADHD.

The survey instrument itself shows promise; excellent alpha coefficients indicate potential to refine the instrument for use in research and clinical settings. Random sampling with regional, socioeconomic and ethnic diversity is needed to assess and strengthen its psychometric properties. A shorter version of the survey might be developed for use with children and families in the clinical arena.

There is a need to learn about whether fathers' perceptions, information needs and management styles are similar to those of mothers and whether, because the higher incidence of ADHD in males, gender affects the parenting role or function. In addition, there is a need to explore how a parent with ADHD functions in the parenting role as compared with parents without ADHD.

In summary, this study asked parents of children with ADHD what information and advice they wished from their primary care provider. Participants indicated that they want information and advice about managing diagnostic features of ADHD that impact daily routines, school, behavior and socialization from their primary care provider. Parents also reported that they both wanted information about the diagnosis and prognosis of ADHD from their primary care provider. In addition, participants wanted care and support from their primary care provider, as demonstrated by an understanding of how ADHD affects the entire family system and by referrals to needed resources. The parents in this study were clear and articulate about their needs from primary care providers.

The results of this study have present value as a stimulus for primary care providers to educate themselves about ADHD and improve care delivered to this population of children and families. In addition, the findings serve as a springboard for future studies that might identify effective parent education and parent training methods adaptable to clinical and research settings, and for further exploration of the family issues related to ADHD.

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Appendix A

Individual Survey Items

Item	Mean	SD	Rank	Category
Picking up after himself or herself.	8.571	1.852	1	R
Managing resistance or refusal to follow routines	8.057	2.300	2	R
Getting my child to write down & bring home assignments, books, etc.	7.774	3.201	3	SC
Getting my child to do homework	7.697	2.984	4	SC
Getting my child to complete his chores on time	7.571	2.649	5	R
Dealing with hitting, throwing or breaking things in anger	7.429	3.202	6	B
Stop interrupting while I am talking with others.	7.400	2.992	7	SO
Stop interrupting while I am talking with others.	7.229	3.172	8	SO
Stop interrupting while I am on the phone.	7.143	3.136	9	SO
Getting my child awake and going in the morning	7.114	3.132	10	SL
Managing when special events interrupt daily routines	7.057	2.980	11	R
Getting my child to stop losing or failing to turn in completed homework	7.032	3.582	12	SC
Knowing what is realistic for an after school routine	7.029	2.640	13	R
Setting limits for verbal abuse: name calling, cursing, etc.	7.029	3.417	14	B
Get along without fighting other children.	6.914	3.193	15	SO
Decreasing my child's behavior problems at school.	6.781	3.489	16	SC
How to get my child to fall asleep more easily.	6.571	3.575	17	SL
Preventing or managing outbursts in public	6.571	3.398	18	B
Knowing what is realistic for a morning routine	6.514	2.984	19	R

(appendix continues)

Item	Mean	SD	Rank	Category
Understanding how my child's medication works and why it is needed.	6.229	3.874	20	M
Knowing what is realistic for a bedtime routine.	6.171	3.063	21	R
Setting limits for spending money on toys, treats, etc.	6.114	2.867	22	B
Teaching manners at the table, on the phone, greeting people, etc.	6.114	3.197	23	B
Knowing what side effects to look for, and how to manage them.	6.086	3.713	24	M
Behave when guests come to our home.	5.914	3.450	25	SO
Rules for TV, when, what and how long to watch.	5.794	2.815	26	B
How to create a routine when none has existed.	5.771	3.639	27	R
Behave in public places.	5.743	3.441	28	SO
Knowing what to tell people about why my child uses medication.	5.657	4.051	29	M
Getting my child to eat the right foods.	5.618	2.582	30	E
Share toys, TV time, games.	5.600	3.117	31	SO
Behave while in the car.	5.471	3.492	32	B
Making a plan both parents can agree on how to handle discipline	5.457	3.943	33	P
Initiating and completing the IEP (individualized education plan) program	5.448	3.491	34	SC
Getting school to follow the IEP (individualized education plan).	5.414	4.067	35	SC
Working out my concerns about using "stimulant" medication.	5.286	3.793	36	M
Any foods my child should or should not have.	5.171	3.618	37	E
How to tell people about my child's ADHD.	5.143	3.882	38	P
Rules for video games: when and how long to play.	5.118	3.189	39	B
Refusing to wear clothes appropriate for the weather.	4.943	3.369	40	D

(appendix continues)

Item	Mean	SD	Rank	Category
Behave at others' homes.	4.914	3.899	41	SO
Should we try a diet for ADHD kids?	4.909	3.548	42	E
Is my child's medicine affecting his sleeping and waking?	4.743	3.898	43	SL
Behave with a baby-sitter.	4.743	3.641	44	SO
Over-sensitivity to the "feel" of fabrics.	4.714	4.077	45	D
Is my child's medicine affecting his appetite?	4.514	3.705	46	E
Establishing and enforcing a bedtime.	4.429	3.673	47	SL
Knowing what foods my child should be eating.	4.353	3.515	48	E
Getting my child to eat enough food at mealtimes.	4.286	2.814	49	E
How to give the medication, and when.	4.171	3.753	50	M
Getting school to give my child's medication on time or at all.	4.147	4.342	51	M
Ideas for healthy snacks	4.059	3.402	52	E
Fighting over bathing and showering.	3.771	3.565	53	D
Managing night waking.	3.771	4.001	54	SL
Insisting that labels be removed from neckline, waistband, etc.	3.686	3.946	55	D
My concerns that I might have ADHD or if I gave it to my child.	3.571	4.132	56	P
Refusing to wear new clothes.	3.314	3.879	57	D
Wanting to wear the same clothes every day.	3.257	3.736	58	D
Getting the physician forms for medication signed and to the school.	2.765	3.627	59	M
How to handle "night prowling" when my child is awake at night.	2.600	3.292	60	SL
Managing bad dreams.	2.485	3.251	61	SL
Getting pharmacy to give second labeled bottle.	2.353	3.228	62	M

(appendix continues)

Item	Mean	SD	Rank	Category
Refusing to wear socks or shoes.	2.086	2.994	63	D
Managing sleep walking.	1.886	2.654	64	SL

Appendix B

Study of Parents of Children with ADHD:

What advice about parenting and managing daily living do parents of a child with ADHD want from their primary care provider?

PURPOSE: You are invited to participate in a research study because you are a parent of a child with ADHD (attention deficit hyperactivity disorder). The purpose of this study is to learn from parents of ADHD children what kinds of advice about parenting and managing daily living you want from your child's primary care provider (your family doctor, pediatrician or nurse practitioner).

The questionnaire asks whether certain situations involving activities of daily living are a problem for you. Each participant will spend between 15-20 minutes of time completing one written questionnaire.

RISKS: There are no known risks associated with participating in this study. Your participation requires only that you complete the survey during this evening's meeting. Participation is completely voluntary and you may decide at any point to end participation without penalty.

BENEFITS: You may or may not personally benefit from participating in this study. However, by serving as a subject, you may contribute new information which may benefit families in the future. The results of this study will be submitted for publication so primary care providers can learn from parents what advice is needed. You may request that a copy of the results be mailed to you.

CONFIDENTIALITY: The information you provide will be kept confidential by the researcher. Your name is not recorded; each questionnaire will be coded with identification numbers. Neither your name nor your identity will be used for publication or publicity purposes.

COSTS: There is no cost associated with participating in this study. Participation in this study is voluntary; you will receive no compensation for participating.

For more information, please leave a voice mail message at: OHSU School of Nursing, 503-494-1509, for Kathleen Shelton.

Appendix C
Parent Survey

ID# _____

PARENT SURVEY

What advice about parenting and managing daily living do parents of a child with ADHD want from their primary care provider?

Survey taken by Kathleen Shelton, RN, PNP, Oregon Health Sciences University Master's Student
Fall, 1995

(appendix continues)

The purpose of this survey is to learn from parents of ADHD children what kinds of advice about parenting and managing daily living you want from your child's primary care provider (your family doctor, pediatrician or nurse practitioner). The results of this survey will be submitted for publication so primary care providers can learn from parents what advice is needed.

On a scale of 0-10, how would you rate the following problems?

	Amount of problem										
	No problem										big problem
Situation: Eating. I would like advice about:											
Getting my child to eat enough food at mealtimes.	0	1	2	3	4	5	6	7	8	9	10
Getting my child to eat the right foods.	0	1	2	3	4	5	6	7	8	9	10
Knowing what foods my child should be eating.	0	1	2	3	4	5	6	7	8	9	10
Any foods my child should or should not have.	0	1	2	3	4	5	6	7	8	9	10
Ideas for healthy snacks.	0	1	2	3	4	5	6	7	8	9	10
Should we try a diet for ADHD kids?	0	1	2	3	4	5	6	7	8	9	10
Is my child's medicine affecting his appetite?	0	1	2	3	4	5	6	7	8	9	10
Situation: Sleeping. I would like advice about:											
Establishing and enforcing a bedtime.	0	1	2	3	4	5	6	7	8	9	10
How to get my child to fall asleep more easily.	0	1	2	3	4	5	6	7	8	9	10
Managing night waking.	0	1	2	3	4	5	6	7	8	9	10
Managing bad dreams.	0	1	2	3	4	5	6	7	8	9	10
Managing sleep walking.	0	1	2	3	4	5	6	7	8	9	10
How to handle "night prowling" when my child is awake at night.	0	1	2	3	4	5	6	7	8	9	10
Getting my child awake and going in the morning.	0	1	2	3	4	5	6	7	8	9	10
Is my child's medicine affecting his sleeping and waking?	0	1	2	3	4	5	6	7	8	9	10
Situation: Dressing. I would like advice dealing with my child's:											
Wanting to wear the same clothes every day.	0	1	2	3	4	5	6	7	8	9	10
Insisting that labels be removed from neckline, waistband, etc.	0	1	2	3	4	5	6	7	8	9	10
Refusing to wear new clothes.	0	1	2	3	4	5	6	7	8	9	10

(appendix continues)

Please circle yes or no and indicate how much each item is a problem:

	Amount of problem										
	No problem										big problem
Situation: Dressing. I would like advice about dealing with:											
Refusing to wear clothes appropriate for the weather.	0	1	2	3	4	5	6	7	8	9	10
Refusing to wear socks or shoes.	0	1	2	3	4	5	6	7	8	9	10
Over-sensitivity to the "feel" of fabrics.	0	1	2	3	4	5	6	7	8	9	10
Fighting over bathing and showering.	0	1	2	3	4	5	6	7	8	9	10
Situation: Routines. I would like advice about:											
Knowing what is realistic for a morning routine.	0	1	2	3	4	5	6	7	8	9	10
Knowing what is realistic for an after school routine.	0	1	2	3	4	5	6	7	8	9	10
Knowing what is realistic for a bedtime routine.	0	1	2	3	4	5	6	7	8	9	10
Managing when special events interrupt daily routines.	0	1	2	3	4	5	6	7	8	9	10
Managing resistance or refusal to follow routines.	0	1	2	3	4	5	6	7	8	9	10
How to create a routine when none has existed.	0	1	2	3	4	5	6	7	8	9	10
Getting my child to complete his chores on time.	0	1	2	3	4	5	6	7	8	9	10
Picking up after himself or herself.	0	1	2	3	4	5	6	7	8	9	10
Situation: Behaviors. I would like advice about:											
Setting limits for verbal abuse: name calling, cursing, etc.	0	1	2	3	4	5	6	7	8	9	10
Setting limits for spending money on toys, treats, etc.	0	1	2	3	4	5	6	7	8	9	10
Dealing with hitting, throwing or breaking things in anger.	0	1	2	3	4	5	6	7	8	9	10
Preventing or managing outbursts in public.	0	1	2	3	4	5	6	7	8	9	10
Teaching manners at the table, on the phone, greeting people, etc.	0	1	2	3	4	5	6	7	8	9	10
Rules for TV, when, what and how long to watch.	0	1	2	3	4	5	6	7	8	9	10
Rules for video games: when and how long to play.	0	1	2	3	4	5	6	7	8	9	10
Situation: Socializing. I would like advice about teaching my child to:											
Get along without fighting other children.	0	1	2	3	4	5	6	7	8	9	10
Share toys, TV time, games.	0	1	2	3	4	5	6	7	8	9	10
Stop interrupting while I am on the phone.	0	1	2	3	4	5	6	7	8	9	10
Stop interrupting while I am talking with others.	0	1	2	3	4	5	6	7	8	9	10

(appendix continues)

Please circle yes or no and indicate how much each item is a problem:

	Amount of problem										
	No problem---big problem										
Situation: Socializing. I would like advice about teaching my child to:											
Stop interrupting while I am talking with others.	0	1	2	3	4	5	6	7	8	9	10
Behave at others' homes.	0	1	2	3	4	5	6	7	8	9	10
Behave when guests come to our home.	0	1	2	3	4	5	6	7	8	9	10
Behave in public places.	0	1	2	3	4	5	6	7	8	9	10
Behave while in the car.	0	1	2	3	4	5	6	7	8	9	10
Behave with a baby-sitter.	0	1	2	3	4	5	6	7	8	9	10
Situation: School. I would like advice about:											
Getting my child to do homework.	0	1	2	3	4	5	6	7	8	9	10
Getting my child to write down & bring home assignments, books, etc.	0	1	2	3	4	5	6	7	8	9	10
Getting my child to stop losing or failing to turn in completed homework.	0	1	2	3	4	5	6	7	8	9	10
Decreasing my child's behavior problems at school.	0	1	2	3	4	5	6	7	8	9	10
Initiating and completing the IEP (individualized education plan) program.	0	1	2	3	4	5	6	7	8	9	10
Getting school to follow the IEP (individualized education plan).	0	1	2	3	4	5	6	7	8	9	10
Situation: Medications. I would like advice about:											
Understanding how my child's medication works and why it is needed.	0	1	2	3	4	5	6	7	8	9	10
How to give the medication, and when.	0	1	2	3	4	5	6	7	8	9	10
Knowing what side effects to look for, and how to manage them.	0	1	2	3	4	5	6	7	8	9	10
Knowing what to tell people about why my child uses medication.	0	1	2	3	4	5	6	7	8	9	10
Working out my concerns about using "stimulant" medication.	0	1	2	3	4	5	6	7	8	9	10
Getting school to give my child's medication on time or at all.	0	1	2	3	4	5	6	7	8	9	10
Getting the physician forms for medication signed and to the school.	0	1	2	3	4	5	6	7	8	9	10
Getting pharmacy to give second labeled bottle.	0	1	2	3	4	5	6	7	8	9	10
Situation: Parenting. I would like advice about:											
Making a plan both parents can agree on how to handle discipline.	0	1	2	3	4	5	6	7	8	9	10
How to tell people about my child's ADHD.	0	1	2	3	4	5	6	7	8	9	10
My concerns that I might have ADHD or if I gave it to my child.	0	1	2	3	4	5	6	7	8	9	10

(appendix continues)

What advice have you received from your primary care provider that was helpful?

What advice would you have liked to receive (but did not get) from your primary care provider?

What advice did you get from your primary care provider that was not helpful?

What things do you want your primary care provider to know about attention deficit hyperactivity disorder and how it affects families?

(appendix continues)

Demographics

About your child with ADHD:

Age: M or F

Grade level this September:

Does your child have an IEP? Y or N

Is your child on medication? Y or N

Which medication and dose?

When was your child diagnosed with ADHD?

Does your child understand about ADHD?

What kind of primary care provider does your child see?

pediatrician family physician nurse practitioner

About you (the child's parent):

Age: M or F

Highest grade completed: 8 9 10 11 12
Years of college: Degree:

Number of children:
Number of children with ADHD:

Marital status:

Have you ever been diagnosed with ADHD? Y N

Has either parent been diagnosed with ADHD? Y N

Other family members with ADHD? Y N

What relation to child? (uncle, sibling, etc.)