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The Impact of Attention Deficit Hyperactivity Disorder (ADHD)

On Families: The Perceptions of Families with an ADHD Child

by

Patrick Whaley

Thesis submitted to the Graduate College of Marshall University

In partial fulfillment of the requirements for the degree of Master of Arts Psychology

Stephen O'Keefe, Ph.D., Committee Chairperson Tony Goudy, Ph.D. Marc Clingan, Ed. D.

ABSTRACT

The Impact of Attention Deficit Hyperactivity Disorder (ADHD) On Families: The Perceptions of Families With an ADHD Child By Patrick Whaley

This study extended the research to include a more complete description of parents' perceptions and the impact had on their family functioning. The researcher selected the participants with two categories in mind: (A) Parents must live or not live with an ADHDdiagnosed child; (B) Parents will provide their consent for this study. The researcher used the Parenting Stress Index (PSI). The PSI is used to identify stress levels in parent-child systems. By using a t-test for independent samples, the treatment group responded with more stress than the control group (T= 10.143, 28). The researcher found a statistically significant difference between the two groups indicating that the ADHD group experiences more stress than the Non-ADHD group. Hopefully, the outcome of this study can supply additional useful information for practicing psychologists, medical doctors, and other members of the mental health community.

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Impact of Attention Deficit Hyperactivity (ADHD) on Family Functioning:

The Perceptions of Families With an ADHD Child

There is adequate research to describe the impact of ADHD-diagnosed children and their parents. However, we lack a complete description of the parent's perception of the impact of their ADHD-diagnosed children. This study will extend the research to include a more complete description of those parents' perceptions. Doing so may allow clinicians to better work on behalf of ADHD-diagnosed children and their families.

Attention deficit hyperactivity disorder (ADHD) is a chronic and pervasive condition characterized by developmental deficiencies in sustained attention, impulse control, and the regulation of motor activity in response to situational demands (American Psychiatric Association, 1987). This diagnosis leads to many problems within the family. Edwards, Schulz, and Long (1995) mentioned that families of children with ADHD have been reported to have difficulties in various aspects of functioning. According to Fischer (1990), studies examining broad areas of functioning have found that parents of children with ADHD report experiencing significantly more stress, feelings of incompetence, and marital discord than parents of children without ADHD.

The parents' perception or perspectives on ADHD can be beneficial when determining a diagnosis and when treatment recommendations are needed. However, parents' perceptions can also create more problems within their family functioning and cause additional problems for the ADHD diagnosis. Sandberg, Weiselberg, & Shaffer (1980) found that maternal reports of mental distress far outweighed the contribution of any other family-background variable (e.g., social class, family size, broken home) in predicting child behavior disturbance, accounting for 73% of the total variance in parental ratings of hyperactivity. Kottman, Robert, and Baker

(1995) found that understanding the perspectives of parents of children with ADHD could assist school counselors and other educators in their efforts to communicate with these parents and to help their children.

Families of children with ADHD have been reported to have difficulties in various aspects of functioning (Edwards, Schulz, & Long, 1995). For instance, Barkley, Fischer, Edelbrock, and Smallfish (1990) found that biological parents of children with ADHD were three times more likely to separate or divorce than parents of children without ADHD. According to Anastopoulos, Guevremont, Shelton, and DuPaul (1992), when parents give more time and energy when dealing with psychological distress and medical problems, less time and energy will be provided to the children. Thus, if parents continue to neglect behavior, it may unintentionally reinforce the child's negative behaviors. This kind of parenting would ultimately yield an increase in the parents' stress. The lived experience of a parent with an ADHD-diagnosed child can be very emotional with many challenges (Taylor 1999). According to Clubb (1991), chronic sorrow is a phenomenon that involves an emotional reaction to the child with a chronic disability. Taylor also noted that "chronic sorrow," as defined by Copley and Bodensteiner "is a plausible emotional phenomenon in parents living with a child with ADHD" Taylor, (1989, p. 36).

Some parents blame themselves for their child's noncompliant behavior Sobol, Ashbourne, Earn, and Cunningham (1989). In Mash & Johnston (1983), the parents reported low levels of self-esteem and high levels of maternal stress (i.e., reports of maternal depression that are correlated with the perceptions of a child with ADHD). Fischer (1990) reports that hyperactive children could create distress for the mother. Barkley et al. (1990) found that mothers of hyperactive adolescents had stressful events in their life. Other studies have also found high

levels of stress within families of children with ADHD (Mash & Johnston, 1983; Anastopoulos, Guevremont, Shelton, & DuPaul, 1992).

In Corkum, Rimer, and Schachar (1999), "the parents' knowledge of ADHD and opinions of the available treatments played an important part in the enrollment of treatments" (p.1043). The authors used the ADHD Knowledge and Opinion Scale (AKOS) to assess parent knowledge of ADHD, including symptoms, characteristics, causes, diagnosis, and treatments of ADHD. According to Corkum, et al., "This study examines the relationship between parents knowledge of attention-deficit hyperactivity disorder (ADHD) and opinions of treatment and their impact on enrollment in and adherences to both pharmacological and nonpharmacological interventions for children with ADHD" (p. 1043).

Lewis (1992) found that "significant problems for the families have also been reported in the areas of parental perceptions, parenting competence, parent-child interaction, and general family atmosphere" (p. 372). An important finding was the perception and lived experience for the parent of a child with ADHD. According to the author, all families went through periodic crisis, ongoing trials, and lifelong worries that were part of the parents' lived experiences.

In contrast to prior research on family functioning (Fischer, 1990), Cunningham, Benness, and Siegel (1988) found that family functioning did not lead to parental hyperactivity. It also found that marital satisfaction and ADHD children were not correlated. This study did agree with Mash & Johnston's (1983) finding that mothers had high depression scores when compared to the husband and mothers of non-ADHD children.

Studying the differences between the perceptions of parents and teachers, Christie, Dewitt, Kaltenbach, and Reed (1984) found that "clearly, parents seem to be most sensitive to

inattention, while teachers tend to be most aware of the hyperactive behavior of these children" (p. 774).

Thompson (1996) commented on her lived experience with an ADHD child: "I would gladly have blamed myself for being a bad parent who did not provide enough discipline rather than admit that anything was wrong with my child" (p. 434). Thompson also stated, "although the challenges facing an ADHD child can seem overwhelming, there is now a sizable body of helpful and sound literature on the disorder. It is my hope that this article has provided readers with a useful perspective and steered them to additional sources of reliable information" (p. 436).

Sheppard (1998) in reference to McCluskey's daughter stated:

School is hard-and life harder-for those with attention deficit disorder.

Adolescents do not have much time for those who do not fit in, who appear to be show-offs and who cannot pick up on the teenage norms.

There were teachers who wanted Amber out of their classes because she was so disruptive (p 45).

According to Clubb (1991), "chronic sorrow is a concept that describes parental psychologic reaction to a child who has special health needs. The term can be applied to all types of chronic disabilities regardless of their degree of severity" (p. 461). The author also stated that chronic sorrow could be "a periodic, rather than continuous, phenomenon" (p. 463). According to Longo and Bond (1984), "the divorce rate did not appear to be affected by the presence of a handicapped child" (p. 464). McCollum (1975) had the same findings for parents with a chronically ill child. Clubb (1991) suggested that parents who have chronically ill children go through a series of stages of chronic sorrow. The stages are periodic, recurring stages of impact, denial, grief and a phase of focusing outward or restitution.

Edwards, Schulz, and Long (1995) stated, "it seems clear that families of children with ADHD are often impacted not only by the ADHD but also by parental and sibling mental health problems and family dysfunction" (p. 379). Therefore, these authors argue that family functioning plays and important role for the clinician's assessment protocol. Olshansky (1962) states, "If the worker accepts the validity of the concept of chronic sorrow, his goal in counseling the parent will be to increase his comfortableness in living with and managing his defective child" (p. 37). Taylor (1999) stated:

The impact of ADHD on parents and children may provide an explanation of how the quality of parent can affect the adjustment of the child with ADHD. Understanding what it is like being the parent of a child who throws tantrums, is full of uncontrolled activities, and does not listen or follow directions is an important aspect of determining this impact (p.1).

According to Copley and Bodensteiner (1987), "expressions of parental grief include symptoms of anxiety, anger, guilt, and depression" (p. 29). Taylor's (1999) study found that chronic sorrow is a normal reaction to an abnormal situation. Parents in this study reported feelings of guilt, anger and sadness at having a child diagnosed with ADHD.

There are several treatment modalities for children with ADHD. The Academic Review (1999) said that treatment involves: pharmacological, behavioral, and cognitive-behavioral modalities. It also stated that 75% of a group of ADHD-diagnosed ch9ildren exacerbated improvement in paying attention during class and on measures of academic efficacy while taking the medication, Ritalin (Kaplan and Saddock, 1996). Pharmacological treatment should not be the only treatment for ADHD. Other forms of psychotherapy will be needed like individual psychotherapy, cognitive-behavioral therapy, and parent counseling. Kaplan and Saddock

(1996), states that when ADHD children are taking medication they should be explained on how important this medication is to them. Doing so will help terminate misconceptions about medication abuse. Kaplan and Saddock (1996) stated that when ADHD children are helped to strengthen their environment, their anxiety diminishes. For instance, the parents and teachers should provide a structure of reward and punishment using a cognitive-behavioral therapy model and applying it to the child's daily life.

Kottman, Robert, and Baker (1995) found that parents with ADHD children need more linkage and referral to the available services in their community. For example, a support group for parents who have children with ADHD or a mental health professional, who provides therapy, may also prescribe appropriate medication. The authors also said that the parents needed new ways for communicating with counselors, pediatricians, teachers, and mental health professionals.

Fischer (1990) suggests:

Depression in parents is thought to heighten their perceptions of child Maladjustment and to increase the number of commands and the amount Of controlling behavior that they exhibit. Presumably, then, depression could act to maintain negative child behaviors, to impair response to treatment offered, and to maintain stress (p. 339).

Taylor (1999) stated:

Grief is a feeling that most parents will experience when confronted with a diagnosis of a chronic condition and parents of children with ADHD are no exception. These parents suffer a great many losses when their children are diagnosed. As the parents struggle to maintain a sense of

normalcy in their lives, they may experience feeling of anger, frustration, and guilt in regards to the cruel blow that had been dealt them (p. 32-33).

According to Thomas and Chess (1977), "parents are often judged as failures for letting their child run wild" (p. 31). Taylor (1999) stated, "No parent is ever quite prepared to cope with the multitude of problems that will confront them when their child is diagnosed with ADHD" (p. 31). The author stated that children with ADHD are frequently seen as troublemakers or bad children with behavior problems. Parents also blame themselves for their child's behavior (Taylor, 1999).

According to Barkley and Edelbrock (1987), "The attention-deficit-disordered/hyperactive ADDH child's problems with restlessness, concentration, and impulse control contribute to a situationally pervasive pattern of difficulties in social relationships with members of the child's family and community" (p. 169).

The parent's of ADHD children have to deal with a lot of stress. Some parents even develop their own mental health problems due to living with an ADHD-diagnosed child. This research study will show how important the impact of family functioning can have on treatment and diagnosis of ADHD. It will also accurately depict the perceptions on ADHD and the effect it has on their family functioning.

Methods

Participants

The volunteers in this study will be selected from two community behavioral health centers (CBHC's) and through interested members of the community. The researcher will need no more than 50 participants. Those participating in this study that live with an ADHD-diagnosed child will be the experimental group. The participants who do not live with and ADHD-diagnosed

child will be part of the control group. All participants in this study will be selected from low to high socio-economic backgrounds, low to high educational levels and from the ages that range from pre-school to adolescence. Any individual from the community behavioral health centers who are interested in becoming a participant will contact the researcher via telephone or by mail. The researcher will get in contact with staff psychiatrists and case managers at the two CBHC's. They will be given an introductory statement (Appendix A), and a business card with contact information (Appendix B) which enables the participant to contact the researcher at their convenience. Thus, the psychiatrist and/or case manager will provide the interested participant with the introductory statement and business card. The researcher will select the participants with three categories in mind: (A) The parent must live or not live with an ADHD-diagnosed child; (B) Researcher must receive a lived experience; (C) Parent must give a lived experience to the researcher. The participant will provide their consent for this study.

Materials

The Parenting Stress Index (PSI) is a 120-item self-report measure developed to identify stress levels in parent-child systems. Items on the PSI are easy to complete. It usually takes parents about 20 minutes to complete the PSI (Mears and Plake, 1998). The PSI items are mostly based on a 5-point Likert style format with the scale ranging from strongly agree to strongly disagree. Few items use the multiple choice and three items are in a 4-point Likert scale format. This test instrument will provide the researcher with detailed information on the family functioning of families that live with an ADHD child.

The researcher also collected the lived experiences of families with ADHD-diagnosed children, after Taylor (1999): "Participants were asked to describe their experience living with a

child with ADHD. They were asked to reflect on thoughts, feelings, and perceptions related to that experience" (p. 12).

Procedure

Once the researcher and participant meet or talk over the phone, the interview will begin. The researcher will use a phone script (Appendix C) to go by if he is contacted via by phone. Otherwise, I will respond to the participant in the same manner that they have contacted me and I will provide them information on how I can be contacted. During the interview, demographic information will be collected. Then, the researcher will ask the participant to describe their lived experiences and to give their perceptions of living with an ADHD-diagnosed child. When the parents' are finished with the interview, the PSI will be administered. After this scale is complete, the parent can terminate the process if they believe that their lived experience and perceptions have been accurately described. The total stress scores from the PSI will be used to determine the significance between the experimental group and the control group. Results of the study will be forwarded to the participants after research is finally completed.

Results

Analysis of Data

The research was an experimental design and a parametric test. The data was calculated by using a t-test between two correlated groups (See Appendix E). Since this experimental design had two correlated groups it met the criteria for being a matched group design, thus, the reason for using a t-test for dependent groups. If the independent variable is a within subjects factor, or if two separate groups of people are formed in such a way that some relationship exist between them (e.g., subjects in group A are matched on intelligence with subjects in group B), a t-test for dependent groups is used (Goodwin, 1998). The t-test will examine the difference of the

means between the two groups. It will determine it there is a significant difference between the ADHD group and the non-ADHD group. The t-test also used an alpha level of .05 with 28 degrees of freedom.

Discussion

The results of this study are similar to previous research on severe stress levels of parents who live with ADHD children (Anastopoulos, 1992, Breen & Barkley, 1998; Mash & Johnston, 1983a). By using a t-test comparison, the experimental group does experience more stress than the control group (Appendix E). The difference between the two means was 147.07 and a t of 10.14. At a confidence interval of 95 percent, the difference of the means was 117.37 to 176.77. So as mentioned earlier since there is a statistical significant difference between the two groups it can be inferred that the ADHD group experiences more stress than the non-ADHD group. Therefore, the results of this study has shown that parents who live with ADHD diagnosed children experience more stress and could possibly have clinical implications from having a child that is diagnosed with ADHD as opposed to families that do not have children diagnosed with ADHD.

Along with many other research studies there is some possible limitations to this experiment design. Some of the possible limitations were the sample size, maturation, and the subject selection. The sample size had 30 participants though the goal was to have 50 participants it still probably would not have been a good representative sample of the ADHD population in north central West Virginia. Another possible confounding variable would have been the maturation effect. For instance, it is possible that during the time of the research that the participant was experiencing or not experiencing large amounts of stress whereas several weeks or months before the research that they did or did not experience any stress. Sometimes the

subject selection is a confound variable. As in Mash & Johnston, 1983a, the subject selection was a possible confounding variable due to the socioeconomic status. The socioeconomic status (SES) of this study as compared to Mash & Johnston, 1983a could have been the same. For instance, the ADHD group could have had a low SES and the non-ADHD group could have had a high SES, which in result would affect the stress levels of the two groups. The limitations mentioned in this study were all possibilities but in order to really validate those limitations, a possible longitudinal research design or a repeated groups design could have been used. A longitudinal research design or a repeated groups design would be beneficial in further research on the stress levels of families with ADHD diagnosed children.

Hopefully, the outcome of this study can supply additional useful information for practicing psychologists, medical doctors, and other important members of the mental health community. It is important to have actual documentation on the reported parental stress levels for the mental health community. It could be useful on further research of ADHD. Additional research on the psychopathology of parents who live with ADHD diagnosed children and their possible implication could also be beneficial. Another important aspect to research is the children's stress levels rather than the parents stress levels along with the complications of having ADHD.

Introduction Statement

My name is Patrick Whaley, I am a graduate student at Marshall University Graduate College. My major at Marshall University is Clinical Psychology. This introduction concerns my Master's thesis, which entails the impact of ADHD on family functioning. I would like to have your participation for this study. Please if you have the time I would greatly appreciate your assistance.

The purpose of this study is to examine the experience of living with a child that has ADHD. I hope this study will help gain a better understanding to enable medical or mental health practitioners to provide healthcare in a manner, which will be responsive to he needs of families with an ADHD child.

If you agree to participate, I will:

- 1. Interview you alone in a mutually agreed upon place or conduct the interview over the phone if you like.
- 2. Ask you to fully describe to the best of your ability, your experience living with a child that has ADHD and to complete the Parenting Stress Index (PSI). The PSI takes about 30 minutes to take.
- 3. Your identity will be protected and not revealed in any way.

This is voluntary and you may with draw at any time with no ill effect on your child's treatment or any provision of service.

Telephone Script

My name is Patrick Whaley. I a	am a graduate student at Marshall University Graduate
College. I was told by	_ that it was all right to contact you about your possibility
participating in a research study that I a	am conducting.

The purpose of this study is to examine the experience of living with a child that has ADHD. I hope this study will help gain a better understanding to enable a medical or mental health practitioner to provide healthcare in a manner, which will be responsive to the needs of families with an ADHD child.

If you agree to participate, I will:

- 1 Interview you alone in a mutually agreed upon place or conduct the interview over the phone if you like.
- 2 Ask you to fully describe to the best of your ability, your experience living with a child that has ADHD and to complete the Parenting Stress Index (PSI). The PSI takes about 30 minutes to take.
- 3 Your identity will be protected and not revealed in any way.

This is voluntary and you may with draw at any time with no ill effect on your child's treatment or any provision of service. Do you have any questions? Would you be willing to participate? When would be a good time for us to meet?

CONSENT FORM

I understand that this is a study concerning the family functioning of either a family that lives with child diagnosed with Attention Deficit Hyperactivity Disorder (ADHD) or a child not diagnosed with ADHD and that knowledge gained is expected to help medical or mental health practitioners in a manner in which will be responsive to the needs of families with an ADHD child or families that do not have a ADHD diagnosed child. I also understand that:

- 1. Participation in this study will involve a informal interview and completing the Parenting Stress Index (PSI) which approximately takes 30 minutes to complete.
- 2. That I have been selected for participation because I have a child diagnosed with or without ADHD.
- 3. It is not anticipated that his study will lead to any physical or emotional risk to it and myself may be helpful just to talk to someone about my experience.
- 4. The information I provide will be kept strictly confidential and the data will be codes so that identification of individual participants will not be possible.

I acknowledge that:

I have been given the opportunity to ask question regarding this research study, and that these questions have been answered to my satisfaction.

In giving my consent, I understand that my participation in this study is voluntary and that I may withdraw at any time with no effect on my child's treatment or any provision of service.

I here by authorize the investigator to release information obtained in this study to Scientific literature. I understand that I will not be identified by name.

articipate in this study.	ead and understood the above information, and that I agree to					
Witness	Parent or Provider's signature					
Date	Date					

T-test

Normality Test: Passed (P=0.056)

Equal Variance Test: Passed (P=0.113)

Group Name	N	Missing	Mean	Std Dev	SEM
ADHD	15	0	324.133	45.00	11.619
Non-ADHD	15	0	177.067	33.593	8.674

Difference 147.067

T=10.143 with 28 degrees of freedom. (P=<0.001).

95 percent confidence interval for difference of means: 117.366 to 176.767

The difference in the mean values of the two groups is greater than would be expected by chance; there is a statistically significant difference between the input groups (P= <0.001).

Power of performed test with alpha = 0.050: 1.000

Attached IRB Form

PSI Subscales

Child Domain Parent Domain

	DI A	AD :	RE	MO	AC	CO	IS	ΑT	HE	RO	DP	SP	Total
ADHD	35	37.7	18.3	26.7	18.2	23.13	36.2	17.1	18.3	14.3	25.8	28	25.3
Non-	19	21.5	8.3	13.3	8.8	8.7	24.4	10	10.9	10.9	12.6	13.9	13.8
ADHD													

Child Domain

DI=Distractibility/Hyperactivity

AD=Adaptability
RE=Reinforces Parent

DE=Demandingness

MO=Mood

AC=Acceptability

Parent Domain

CO=Competence

IS=Isolation

AT=Attachment

HE=Health

RO=Role Restriction

DP=Depression

SP=Spouse

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