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Mike Schneider
Medicating Attention-
Deficit/Hyperactivity Disorder in
Children and Adolescents: How do
Parents/Guardians Decide?

ABSTRACT

This project was undertaken to obtain a better understanding of how parents/guardians reach the decision whether or not to medicate their child diagnosed with Attention-Deficit/Hyperactivity Disorder (ADHD). There has been a great deal of research done on ADHD that deals with aspects such as treatment interventions, side effects of psychotropic medication, and comparing behavioral to medicinal treatment; however, little research has been done examining how these treatment interventions are arrived upon for these children. This study attempted to offer data to identify what parents/guardians feel work and does not work while leaving the door open for further research in this area.

A total of 26 anonymous parents/guardians who had a child diagnosed with ADHD were the participants in this study a flexible methods design with open ended questions. Each participant answered an anonymous survey online and was asked the same 12 questions. The instrument used in this study was a qualitative questionnaire that explored how parents/guardians navigated through their decision making process on whether to or not to medicate their child with ADHD.

This study implies a need for more research as participation was limited. The findings do show some emerging themes that would be beneficial to examine further. ADHD is a growing epidemic in the United States and understanding how one takes their first steps when treating their child should be seen as a vital factor in ongoing research.

MEDICATING ATTENTION-DEFICIT/HYPERACTIVITY
DISORDER IN CHILDREN AND ADOLESCENTS:
HOW DO PARENTS/GUARDIANS DECIDE?

A project based on an independent investigation, submitted in partial fulfillment of the
requirements of the degree of Master of Social Work

Mike Schneider

Smith College School for Social Work
Northampton, MA 01063

2014

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Chapter I

Introduction

The following study was inspired by a growing epidemic surrounding the clinical diagnosis Attention-Deficit Hyperactivity Disorder (ADHD). Children and adolescents are being diagnosed with ADHD at increasing levels every year (Vaughan, Roberts, & Needleman, 2009). As of 2010, approximately 56% of youth aged four to 17 years old diagnosed with ADHD were taking psychotropic medication as part of their treatment (Batzle, Weyandt, Janusis, & DeVietti, 2010). Many of these youth are concurrently being put onto ADHD medication shortly after their diagnosis with little intervention being explored beforehand (Johnston & Leung, 2001). Furthermore, these psychotropic medications have proven side effects such as loss of appetite, weight, and stability (Johnston & Leung, 2001). This study will examine how parents navigate their child's ADHD diagnosis and decide whether or not psychotropic medication will be involved in their treatment.

There are several reasons why this topic should be researched further starting with the fact that there is still no clear answer on what the role of medication should play in the treatment process for those diagnosed with ADHD. Also, while children who have an ADHD diagnosis who are put on medication have been found to have a 66 percent success rate in reducing symptoms of ADHD in one study, the same study found that these medications had side effects such as insomnia, loss of appetite, weightless, and stunted growth as the leading examples (Vaughan, Roberts, & Needleman, 2009). For social work practice in particular, answers to

questions surrounding this topic will help therapists conduct the most effective interventions when working with children who have been diagnosed with or referred to a social worker for symptoms of ADHD. They will then be more able to execute strategies and treatment plans with all parties involved.

It is the primary goal of this research study to contribute to social work practice and related fields data that will assist parents/guardians with their child diagnosed with ADHD. The information gathered will focus on how decisions are made to medicate children with ADHD symptoms and whether or not those choices garner effective outcomes as defined by parents. The research question explored in the following study was: How do parents/guardians decide what treatment interventions to use when their child has been diagnosed with ADHD?

Chapter II

Literature Review

Introduction

Over the past two decades, pharmaceutical, university, and clinical researchers have conducted thousands of studies to determine the positive and negative effects that medicinal and/or behavior interventions have on children with ADHD. Research on this topic also incorporates feedback from parents, school teachers, and children themselves in their methodologies. This review will examine these studies, their results, and make recommendations for future research based on their limitations.

Overview

Currently, ADHD is the most commonly diagnosed behavioral disorder in children and approximately three to five percent of school-age children have been diagnosed with this disorder. Some estimates range as high as seven to twelve percent of children having been diagnosed or between one and a half to six million children total. A recent study from 2013 shows an approximate increase from 56 percent in 2010 to about 80 percent of children diagnosed with ADHD are now being treated with psychotropic medication (Bokhari & Fournier, 2013). Doctors are diagnosing children and adolescents with Attention Deficit Hyperactivity Disorder (ADHD) at higher levels every year (Vaughan, Roberts, & Needleman, 2009). The number of prescriptions written for stimulant medication to treat ADHD between 1991 and 2008 increased by 500% (Dunne, 2008). As of 2010, approximately 56 percent of

youth aged four to 17 years old diagnosed with ADHD took psychotropic medication as part of their treatment (Batzle, Weyandt, Janusis, & DeVietti, 2010). The demand for drugs to treat ADHD has grown rapidly in the past decade. It should also be noted that the majority of children and adolescents who receive stimulants for ADHD do not fully meet the criteria for ADHD, while many children who do meet the criteria for ADHD are not being treated (Dunne, 2008).

Psychotropic versus Psychosocial Treatment Interventions

Research suggests that psychotropic medication, in general, can have a positive effect on a person's ability to focus, learn, and function daily with little to no inattentive, hyperactive, and/or impulsive behaviors (DuPaul & Stoner, 2003). That being said, other research suggests psychotropic medication, especially when used with children and adolescents can be detrimental to a person's overall well being (Vaughan, Roberts, & Needelman, 2009). A great deal of research shows that using behavioral interventions to treat ADHD produces mixed results. (Abramowitz, Eckstrand, O'leary, & Dulcan, 1992). Many still debate whether medication, behavioral interventions, or a combination of the two is the best treatment option.

A recent study found that medication reduced ADHD symptoms in the majority of its participants, but also produced many side effects including insomnia, loss of appetite, mood disorders, and stunted growth/weight loss (Bailey, Derefinko, Milich, Lorch, & Metze, 2011). Another study concluded that ADHD medication alone might not be sufficient for treating ADHD in children. Although the results state that stimulants are effective in 80 percent of children who take them, it is concluded that behavior modification and combined behavioral–pharmacological approaches are effective for decreasing symptoms associated with ADHD at both home and school (Vaughan, Roberts, & Needelman, 2009). Behavioral interventions should be components of treatment of children with ADHD as they may help families cope with the

chronic nature of the disorder. These studies collectively report that although medication may increase productivity in general, it may not be sufficient to improve long-term memory or inattentiveness symptoms without behavior interventions.

One limitation to these studies is that the researchers are identifying what they deem as a positive and negative side effect whereas the participants and their families might disagree. Also, parents with limited knowledge about ADHD medication are less likely to incorporate it into their child's treatment plan as reported by parents themselves. Including education on the ADHD diagnosis and the medication seems imperative to be all inclusive.

This leads to the discussion on how parents and school teachers are a vital part of the treatment process. Studies have shown that children with ADHD are positively affected when their parents and teachers are involved in their treatment (Leggett, & Hotham, 2011). In a relatively new study, researchers examined psychosocial interventions involving parents and teachers whose children and students respectively were diagnosed with ADHD. In this research, approximately half of the children were on medication. The main component to their hypothesis is that a family-school success (FSS) program would be more effective than other limiting existing multimodal treatments for ADHD. The study found that all parties involved felt well informed of their child's strengths and weaknesses and were able to collectively work to resolve any concerns. Most importantly was discovering that being consistent with interventions at school and home is an effective strategy (Power, Mautone, Soffer, Clarke, Marshall, Sharman, & Jawad, 2012). Together these studies reported that the results were virtually the same in the level of effectiveness regarding academic performance and behavior when comparing the outcomes of behavior vs. medicinal interventions. This suggests that ADHD medication can be equally as effective as a behavioral intervention with cohesive parent-teacher involvement. Also worth

noting in their findings was that most parents were hesitant about putting their child on medication and tried other alternatives first. Most of these parents ended up starting their child on medication if other interventions were failing to decrease or stop their child's ADHD symptoms.

One major limitation for these studies is that parents/families who were difficult to engage (i.e. not responsive to requests to complete surveys, questionnaires, etc. on time) were generally left out and therefore severely underrepresented. Had these participants been included in the results perhaps they would not have been split so evenly. It is possible parents who felt negatively about this particular study were the ones who did not participate which possibly skewed the results.

Children, Parents', and Teachers' Perspectives on ADHD

When tackling the issue of ADHD, three major groups of individuals involved in this process are parents, teachers, and the children diagnosed with ADHD, whose perspectives on interventions are all important when discussing treatment options. Parents normally have the benefit of life experiences to help when it comes to raising their children; however, when their children receive an ADHD diagnosis they are likely learning everything for the first time simultaneously with their child. This can potentially lead to parents wanting to "get out ahead" of their child by ultimately making quicker decisions, whether effective or not, without exploring other options. In a study that involved extensive interviews with mothers of children with ADHD, the findings document that the mothers see ADHD as a legitimate medical diagnosis and view themselves as caretakers of children with brain and neuro-chemical anomalies affecting the behavior of their children. They favor pharmaceutical use and describe themselves as experts in the difficult and complex issues related to pharmaceuticalized parenting. The mothers in this

study were also dismissive of the idea not to use medication on their children and also on using behavioral interventions which they mostly admit to never trying (Clarke & Lang, 2012).

Contradictorily, another study concluded that parents were hesitant about using medication on their children and wanted to attempt other interventions first (Power, Mautone, Soffer, Clarke, Marshall, Sharman, & Jawad, 2012). A recent study examined teacher's responses to questionnaires that presented them with scenarios regarding students with no label, an ADHD label, and an ADHD label taking psychotropic medication. The researchers found that teachers rated the children with ADHD and ADHD with stimulant treatment label less favorably than the child with no label (Batzle, Weyandt, Janusis, & DeVietti, 2010). This suggests that children are dealing with a bias from their teachers meaning that the results found with medication are likely understated.

Children who are diagnosed and being treated for ADHD have their own opinions on how their symptoms are affecting them and how they can best be treated. One study identified attitudes of teenagers about how they thought ADHD medication would affect them before being prescribed their medication. Researchers found in the teenagers' self-reports that they felt their hyperactive, impulsive, and/or inattentive behaviors would improve with medication, specifically with school work. However, as it relates to the other parts of their lives they reported thinking taking medication would affect their moods and make them "not fun" people to be around (Cox, Davis, Burket, Merkel, & Mikami, 2012). These studies collectively show the range of how different perspectives vary and that students that have an ADHD diagnosis are looked down upon especially by teachers. With parents unsure about the best treatment options, teachers stigmatizing their students with ADHD, and children/adolescents with ADHD worried about being labeled and how medication could negatively affect their personalities and daily

functioning, it is easy to see how treatment is dependent on all three components working cohesively. This being said, the children in these studies mostly believed medication would help them in school while most parents found medication effective for assisting with ADHD symptoms. Essentially, the findings in these particular studies are complex suggesting more research is needed for more conclusive data.

Each of these studies focuses on one of the three components that have been laid out and perhaps this is their main limitation. Future studies on perspectives would garner more helpful responses if each component could express their opinions and then be able to reflect on what the other two components stated as well.

Limitations

Limitations to these studies are many, but a few stand out more so than others. Overall, each of these studies has similar limitations in regards to sample size, gender, and racial identifiers. For example, a few aforementioned studies included small sample sized groups that were not especially diverse in ethnicity, social class, and/or religion. While it would be difficult with most of these studies to have larger sample sizes, they could at least be more representative of all races and gender identities. It appears that the majority of participants have been male and a good number have been White. Also, the studies involving following children on medication lacked a control group of parents who decided against the medication for their child. Furthermore, the exact types of medication were not always listed which is something that should be examined in the future when working with children on ADHD stimulants. Each medication used works differently with each child. Lastly, none of these studies speaks to the mental and physical development affects of medication on these child participants that are being studied.

How do Parents Decide?

All of the previously mentioned studies examined what happens after the treatment decisions are made by parents and followed by their children and collateral contacts involved. What has not been researched extensively enough is how parents are arriving at their decisions how their children with ADHD will best be treated. One study found that parents engage in a process of "doing what helps most" in deciding to use medication to treat their child's ADHD. It concluded that interventions to support and guide parents throughout the decision making process are critical to meeting the needs of families of children with ADHD (Cormier, 2012). What needs to be examined more thoroughly is why the dilemma on how to treat children with ADHD continues to exist and how parents can best navigate through this process to achieve the best outcome for their children.

In conclusion, this literature review has given an overview of the epidemic that is ADHD, how children are being treated for it, and the results of these interventions. Also, the perspectives of children, teachers, and parents were discussed to appreciate the importance of a cohesive front from all parties involved in treatment interventions. This paper will continue to examine the question how do parents arrive at the decision of whether or not to medicate their children diagnosed with ADHD in the following chapters.

Chapter III

Methodology

While there are many studies dealing with ADHD in children, they are primarily focused on efficacy research related to interventions, both behavioral (Leggett, C., & Hotham, E., 2011) and medicinal (Prasad, V., Brogan, E., Mulvaney, C., Grainge, M., Stanton, W., & Sayal, K., 2013). These studies zoned in on topics such as the side of effects of ADHD medication (Vaughan, B.S., Roberts, H.J., & Needelman, H., 2009) and the perspectives of those involved such as teachers, parents, and the children who were diagnosed (Visser, S.N., 2013 and Batzle, C.S., Weyandt, L. L., Janusis, G.M., & DeVietti, T.L., 2010). However, what these studies lacked was that they did not look at the beginning of the process for parents/guardians and how parents and guardians navigated their way through decision-making about how to treat their child. Furthermore, there is little research done on this area of ADHD which makes the need for such a study to exist.

The qualitative design for this study was driven primarily through the researcher's informed personal preference of valuing and collecting peoples' own first hand experiences. Drawing from personal conversations with contacts and past qualitative research studies helped design how the survey questions were formatted. The researched literature has qualitative interviews with children, parents, therapists, and school staff, and the questionnaire was influenced by each of these research studies.

An important aspect to the survey was the open-ended layout that removed leading questions thereby limiting intentional, and unintentional, bias while keeping the integrity of the qualitative design intact. These questions included, but were not limited to, the perception of the child's behavior before treatment, knowledge of medical and behavioral interventions before treatment, how understanding of medicinal side effects affected decision process, and how support systems are formed to discuss this topic based off of sociocultural information. This helped me plan out what and how to ask participants about this process.

Sample

Participants in this study were parents of children diagnosed with ADHD. There were no other eligibility requirements and the goal was to recruit 50 participants. Participants were self-reported parents/guardians of a child diagnosed with ADHD. The aim was to have a diverse group of participants recruited from different populations across the country. The research question was: How do parents/guardians reach the decision on whether or not to start their child diagnosed with ADHD on medication?

Recruitment

My study, and recruitment plan, was approved by Smith School for Social Work's Human Subjects Review board. I recruited participants through personal networks via snowball sampling. I asked contacts who worked with this population for their help recruiting participants (i.e. therapists, psychiatrists, MDs, counselors, and teachers). I sent an email to these contacts explaining my study, which included text to forward to others and a link to the questionnaire (appendix B). I requested that they forward that email to potential participants. I used social networking to recruit participants via my Facebook page. I did not seek clients from anyone, though participants may have been someone's clients.

Data Collection

Participants took part in a 13 question open-ended electronic survey designed by the researcher. These questions were primarily informed by conversations with professionals and colleagues, as well as the researcher's own contacts that have dealt with this topic as a parent, teacher, etc. The questions were also influenced by past qualitative studies on this topic. The data was collected via an online survey tool, survey monkey. Participants accessed the Survey Monkey Website through a direct link that was provided. As the survey is anonymous, the consent was done online according to Smith HSR policies. There was a study description page and an informed consent page (Appendix C). The consent was done electronically a form did not need to be sent back to the researcher. After reading and consenting, the survey began. Parents/guardians were asked a range of questions focusing on their experience discovering their child's ADHD diagnosis and their subsequent journey learning about ADHD and starting treatment in some capacity. Upon submission of the survey, their participation was completed.

Data Analysis

Data was collected from the completed surveys through Survey Monkey. All questions required a response and individuals who fully completed the survey had their data included in analysis. Participants were coded numerically in the order that they submitted the survey and only the researcher and research advisor had access to the data. All information collected was summarized for the purpose of dissemination. The demographic information was organized nominally by numbers into categories for each question. All qualitative data were analyzed and organized into themes as the researcher's intent in this study was to analyze areas where patterns in decisions existed and, if patterns did not appear, explore why not.

Chapter IV

Findings

This was an exploratory study using a mixed methods design. The purpose of the study was to examine the process of how parents come to the decision to medicate their children diagnosed with ADHD. There was also an interest in assessing how socio-cultural factors affected the decision making process. The sample consisted of 26 parents who had a child diagnosed with ADHD. There were not any restrictions placed on either the parents or children as long as they met the aforementioned qualification. This chapter contains a description of the sample of the quantitative data including participant characteristics and societal factors and the findings from the qualitative questions. The sample size is small in this study and should not be viewed as reliable data. However, there are clear themes that emerge that would be beneficial to examine further which will be described in the discussion section.

Table 1. Selected Socio-Demographic Characteristics of the Sample (N=26)

| Background Characteristics | Percent (rounded) |
|-------------------------------------|-------------------|
| Gender of Participant | |
| Male | 34.6 |
| Female | 65.4 |
| Age | |
| <35 or >64 | 11.4 |
| 35-44 | 23.1 |
| 45-54 | 30.6 |
| 55-64 | 34.6 |
| Religion | |
| Protestantism | 15.4 |
| Catholicism | 19.2 |
| Christianity | 11.4 |
| Judaism | 42.3 |
| Islam | 0.0 |
| Buddhism | 11.4 |
| Hinduism | 0.0 |
| Native American | 0.0 |
| Inter/Non-Denominational | 0.0 |
| No Religion | 7.7 |
| Race | |
| White | 84.5 |
| Black or African American | 7.7 |
| American Indian or Alaskan Native | 0.0 |
| Narrative Hawaiian/Pacific Islander | 0.0 |
| From Multiple Races | 0.0 |
| Other (Asian, Hispanic) | 7.7 |
| Annual Household Income | |
| \$0-49,999 | 11.4 |
| \$50,000-99,999 | 19.2 |
| \$100,000-149,999 | 34.6 |
| \$150,000-200,000 | 26.9 |
| \$200,000 and up | 7.7 |
| Primary Language | |
| English | 100.0 |
| Spanish | 0.0 |
| Chinese | 0.0 |
| Portuguese | 0.0 |
| Vietnamese | 0.0 |
| French | 0.0 |
| Other | 0.0 |

| | |
|---|------|
| Highest Level of Education Completed | |
| Some High School | 0.0 |
| Graduated From High School | 7.7 |
| Some College | 19.2 |
| Graduated From College | 30.1 |
| Some Graduate School | 15.4 |
| Completed Graduate School | 26.9 |
| Gender of Child with ADHD Diagnosis | |
| Male | 65.4 |
| Female | 34.6 |
| Other | 0.0 |
| Age of Diagnosis | |
| 4-6 | 11.4 |
| 7-8 | 50.0 |
| 9-10 | 15.4 |
| 11-12 | 7.7 |
| 13-14 | 15.4 |

Demographics of the Participants

This chapter is comprised of the responses of 26 parents whose children were diagnosed with ADHD. The participants were made up of 17 females and nine males while the gender of their children was made up of 17 males and nine females. The average age of participants was 45-64 years old with several being 35-44 and only two being between 18 and 34 years old. The participants were asked to identify the age at which their child was diagnosed and the average response was seven to eight years old with two or less at ages four to 14 save for three 13 year old diagnoses. The participants were asked to identify their race with the majority responding as White with two answering Black or African-American and one answering Hispanic. When identifying religion the majority was Jewish, likely due to this writer's personal recruitment contacts, with approximately four to six each being Protestant, Christian, Catholic, and/or Buddhist (three answered with two identifiers) and two reported no religious affiliations. All participants identified English as their primary language. When asked about the annual

household income the responses did not show any majority with several answering between 50K and 200K and one to two for many incomes above, below, and in between those values.

Important to note based off of this information is the unlikely event that any participant was Medicaid eligible which may have impacted these findings. When asked about their education the majority stated they either finished college or graduate school with several finishing their education with some college or some graduate schooling and only two who completed high school (there were not any participants without a high school degree).

Results

Each participant was asked to answer 12 open ended questions relating to their experience with navigating their child's ADHD. The first question focused on the circumstances surrounding their child's diagnosis which produced thematic responses. For boys younger than 12 participants identified hyperactivity, inattentiveness, and poor grades as primary concerns. For younger girls, however, participants only identified inattentiveness and poor grades without any hyperactivity being present. For both boys and girls 12 and older participants did not report hyperactivity as a concern but rather inattentive behaviors mixed with poor grades.

When asked to discuss how they felt about their child's diagnosis the responses were split almost evenly. Approximately half of the participants expressed confusion and/or uncertainty in upon receiving the diagnosis while the other half approximately reported feeling confirmation for what they seemed to already know and/or relief. Some parents spoke about their confusion with statements such as, "The diagnosis was not definitive; some doctors believed he was borderline, others that he was ADHD" and "I was in disbelief." At the same time other parents agreed with the diagnosis and felt relieved and stated, "I was more relieved to be told that we had a diagnosis

than what I was told by teachers which was they were "delayed" and or not ready for school" and "It was an answer to a question." The few outliers were parents of the older children who had doubts about the diagnosis because they either felt their child was too old to have ADHD or their symptoms were the result of other factors in their lives.

The following two questions were asked as a way to compare and contrast what parents perceived to be the behavioral and academic struggles their children were facing versus what collaterals (i.e. school faculty, doctors, therapists) believed to be the challenges or concerns. The parents reported similar behaviors of hyperactivity, difficulty following directions, inattentiveness, and frustration along with declining grades for the boys under 12 years of age. One parent said of their son, "He had impulsive behavior; an inability to stay focused, and had hyperactivity resulting in academic and behavioral issues." Girls less than twelve years of age had similar symptoms reported but hyperactivity was less frequently endorsed by their parents. One female's parent reported that her daughter "Had difficulty following a concept from start to finish. Classes that required retention to proceed, such as foreign languages, were very difficult." For the older children aged 12 and above the replies showed more of a focus on inner frustration and anger with themselves along with going to school. There were also responses where parents of older children discussed other factors in their lives possibly affecting their children's moods, attention, and grades. For example, one parent said of their older son, "He had trouble focusing and had also gone to three different schools in three years."

Many participants identified organizational issues as well which included children of all ages and genders. The collateral accounts were primarily from teachers who mostly had similar views. They reported with the younger boys and girls an inability to sit still, follow directions, and frustration towards themselves. The one difference reported is that the younger boys also

displayed aggressive behaviors in class. Primarily with the young adolescents it was reported that the concerns were inattentiveness along with feelings of self doubt and frustration. A few outliers were responses saying teachers assumed other motivations for poor work: “This was a struggle, as many teachers didn't believe in this type of diagnosis. Receiving needed leaning tools from the school system was a constant battle. Furthermore, some responses indicated that teachers did not believe in the ADHD diagnosis and would resort to discipline and singling out of child.” Another parent stated: Teachers would always single him out as a trouble child; they never gave him a chance and would always blame him for class problems.”

The participants were then asked to list in chronological order what they did in order to resolve the concerns and what the results were of these actions. The responses were mixed regardless of gender and age as almost each participant reported trying different methods. A few participants reported speaking to everyone involved including their child, teachers, counselors, doctors, and/or therapists. For example, one parent listed their four steps as being: “1. Special preschool: one-on-one involvement and group therapy for parents. 2. Behavioral: for every action there is a result. Acting out would be met with restricting TV and other goodies. Time-out didn't work. 3. Tried to closely coordinate with teachers; a "behavior book" was kept by teacher and sent home to me so child couldn't prevaricate. 4. School finally said he needed to be in Special Education. We fought it.” For many this led to the ADHD diagnosis and their children being prescribed psychotropic medications for the hyperactive and/or inattentive symptoms. The medication reportedly helped most children, especially when combined with other behavioral interventions and/or extra help such as tutoring services. One parent said they “Talked to her doctor who suggested therapy. The therapist referred her to a psychiatrist who prescribed medication which helped her focus better and grades started to improve.” Other parents

attempted strategies such as more discipline, an increase in structure/routine, working more with their child on homework, and/or starting their child in therapy. One parent reported “setting limits and boundaries; tried using reward charts, preferential seating, FBA at school. Behavior remained unchanged.” Approximately half of these participants reported consulting a doctor and trying psychotropic medications after their attempts at resolving their child’s behaviors were unsuccessful.

The next three questions asked participants to identify if ADHD medication was suggested, who made the suggestion, and whether or not they started their child on medication with or without said suggestion. All 26 respondents reported that psychotropic medication was suggested in order to treat their child’s ADHD symptoms. These opinions came from pediatricians, psychologists, therapists, psychiatrists, and school guidance counselors. Of the 26 participants only four parents did not start their child on psychotropic medication after it was suggested. One of these three participants reported trying their own remedies instead, while another of these three stated they were worried about the long term effects. One of these four participants eventually tried medication but reported working with their child might have been equally effective. Of the other 22 respondents it was reported they started their children on medication because they were worried, felt pressured by the school, did not know what else they could do, and/or felt they had tried everything else and nothing was working.

Participants were then asked to discuss what they would have done the same and/or differently if given the chance to start the process over at the time of the diagnosis. Approximately half of the parents responded that they would do everything the same as the behavioral and medicinal interventions used were effective in decreasing/eliminating ADHD symptoms. An example is a parent who stated “I would do the same; Teachers in 2nd Grade

noticed immediate improvement when on the medication.” Six of the respondents reported feeling unsure if they would choose the same path. One parent reported they “would have held off on the medication for a little longer; I think we were too quick.” The remaining six participants stated they would not choose the same path if given a second chance. These parents reported they would try holding off on medication until the problem(s) are clearer, try more tutoring, challenge the school more on their beliefs, explore other possible diagnoses such as anxiety or depression in therapy, change their child’s diet, and/or try increase structure. For example, one parent said, “No, I wouldn't have put him on any medications, because he grew out of his ADHD”

The last question the participants were asked relating to their experience was what they felt were the most effective measures in the treatment of their child with ADHD. The majority of parents responded with a combination of patience, behavioral modification, psychotropic medication, and/or therapy. One parent stated, “Medication and structure were the most effective. We were able to schedule in medication holidays where she was able to regain her appetite. She eventually was able to stop taking the medication.” Many participants stated tutoring helped their child academically as well. An outlier that only a couple participants identified is for parents and schools to recognize that children need outlets for their energy and extracurricular activities can provide assistance with hyperactive children (i.e. “Fencing. An activity your child is enthusiastic about to release energy”). One parent identified building self-esteem as an important factor in their treatment process while another parent stated understanding how your child learns and working with them this way for some time before jumping to therapy and medication.

The final two questions asked parents to identify if there were any other questions they felt should have been asked on the survey and if there was anything else they felt this researcher should know their experiences. Approximately two-thirds of the respondents chose not to answer one or both of these questions as they were both optional. Questions thought up by respondents included asking about their child's self esteem levels before and after treatment, exploring when children have other diagnoses along with ADHD, surveying if parents believe medication is overly prescribed, looking into how relationships are affected within the household with different family members, discussing what is most effective for collaterals to do when working with their children with ADHD, and what kind of training did the teachers have with children diagnosed with ADHD. Regarding what participants wanted this writer to know was that medication should be carefully considered as there are clear positives and negatives with medical interventions. Some participants stated the importance again of working with your child and collaterals to find the best solutions as each child will need different interventions. One parent said they felt that schools and parents can act too quickly without fully understanding what the problem is and that this can lead to more bad than good outcomes. Several participants felt this was a good and even necessary survey and would like to see topic continue to be researched further.

Summary

This chapter presents and summarizes the findings of 26 surveys with parents of children diagnosed with ADHD. Participants were asked 11 demographic questions followed by 12 open ended questions regarding discovering their child's ADHD diagnosis and how they navigated treatment. The majority of these questions saw a mixture of responses based on age and gender of the child, however, the one answer all respondents unanimously gave was that it was suggested that their children start on psychotropic medication once they were diagnosed. The

following chapter will discuss these findings and the relevance to the previously reviewed literature. Furthermore, it will consider the implications of the data and the relationship to social work practice.

Chapter V

Discussion

This study aimed to explore the efficacy of psychotropic medication as an ADHD treatment intervention for children and adolescents as well as determine why parents/guardians opted for or declined this option. This research was also intended to reveal how these parents/guardians navigate treatment upon identifying initial symptoms and consulting professionals. The specific research question analyzed was: How do parents/guardians decide whether or not to medicate their child diagnosed with ADHD?

The narrative suggests that psychotropic medication is a primary treatment intervention for children and adolescents diagnosed with ADHD. Per repetition in the literature, the researcher expected doctors to frequently recommend medication and, consequently, integrated into the treatment plan for the children examined in this study. Furthermore, this researcher expected mixed results in regards to parents' beliefs on medication being the most effective intervention. While doctors recommended medication for every participant, parents' experiences of medication assisted treatment had varying results.

As discussed in the previous chapter, the principle findings of this study were that: 1. Hyperactivity and inattentiveness are present in latency aged boys while only the latter is mainly identified as the problem area in latency aged girls and adolescents of both genders. 2. Parent's reactions when learning of their child's diagnosis were evenly split between confusion/disbelief

and agreement/relief. 3. The majority of parents reported issues at school being the main and/or only cause for the initial push towards finding out if their child has ADHD. 4. All participants had at least one collateral contact tell them they believed their child had ADHD. 5. Most parents reported organizational, structural, attention, and/or poor academia concerns to be the core issues. 6. While many participants took different actions initially after their child was diagnosed, all consulted a doctor who suggested psychotropic medication. 7. Most parents started the children on medication with the majority seeing positive results; however, parents who used behavioral interventions instead also reported a decrease in symptoms. 8. When deciding whether they would take the same approach if given a second chance the participants offered mixed reactions of confidence and uncertainty. 9. The most effective treatment interventions were medication, therapy, and behavioral interventions in that order and often combined. 10. It was agreed by most the more exploration and patience is needed with this diagnosis to better comprehend and choose the best treatment interventions for their children.

These findings contain several unexpected/surprising themes. For instance, it is intriguing that every participant reported having medication suggested as a treatment intervention for their child. With the mixed responses about how parents felt about medication before treatment, it is interesting that not one doctor or clinician felt a non medicinal direction was a viable option. This raises the question as to how, or if, parents raise their concerns, if any, with their doctor or clinician. Or perhaps the doctors may have alleviated the parents' concerns before they addressed them. Furthermore, in the replies it is intriguing how with all the different ages, genders, and behavioral concerns that each clinician/doctor felt almost identically about their treatment approach while many parents were able to find a variety of at least partial solutions to their child's symptoms. It would be worth looking at further with a larger sample size exactly how the

consultations go between parents, child, and doctor/clinician and how soon medication is suggested as a treatment option.

Lastly, it is worth noting that many of the parents participating in this study reported feeling confused and/or uncertain about their child's initial ADHD diagnosis. Even with a minimally diverse sample, it was still evident that many parents felt unsure what to do and were left to follow recommendations by schools and doctors whom they felt did not necessarily know what was best for their child. With a larger, more diverse sample size (i.e. families with lower incomes, primary language other than English, and single parent households) it is likely this theme would not only continue to emerge, but become clear that parents need more education to learn how to speak with their child, schools, and professional clinicians on the topic of treating their child for ADHD. The other side to this is that many participants also stated they felt relieved when their child was diagnosed. This feeling of relief potentially made following suggestions from others (i.e. schools, doctors) easier without exploring as much on their own other possible options.

In the following section, the strengths and limitations of the study will be addressed, as well as the implication for future research.

Strengths

There were several strengths to this study starting with its anonymity factor. Due to this, it is likely participants felt more comfortable reporting personal information (i.e. socio-demographic characteristics). Furthermore, many participants probably did not shy away from honesty in their answers as any feelings of shame or guilt would have been diminished considerably. A debatable strength in this study was the online questionnaire format. By being

able to complete the survey online this allowed participants unlimited time to think about their replies and be as thorough as they wanted. The downside to this format will be discussed in the limitations portion of this chapter. Another strength to this study was that it examined a part of ADHD that has not been heavily researched in the past. This is important in identifying themes that appear in different groups which one can look at those participants information and explore what piece may have assisted in a particular outcome. In the area of religion and age the majority of participants were middle aged, Jewish people. This was a strength to this study because it helps identify one specific population's process. This acts as a limitation as well which will be discussed later in this chapter. Also, even with the small sample size, clear themes emerged in several areas. Finally, the questions relating to the chronological order of how they navigated through the process and what they would have done differently are original ideas. Former research on treatment sequencing would be challenging to find.

Limitations

As with any study, this research had its share of limitations preventing its full potential. While the online survey was seen as a strength to this study, it also acted as a weakness simultaneously. The questions asked to the participants were open ended; however, several parents gave answers where a follow up question might have been helpful to elaborate a fuller response. In face to face interviews a researcher can ask follow up and clarifying questions which can lead to more sensible data at times. Also, some participants may have found it easier to speak about their experience rather than write about it. Another limitation to this study was its sample size. With only 26 participants the data collected is challenging to deem reliable even with emerging themes. It was a difficult population to recruit and having to rely on personal contacts to assist in the process ultimately led to certain demographic categories being

overwhelmingly represented. This is a weakness to using snowball sampling as a recruitment strategy. The three areas in particular for this study being financial income, religion, and primary language. Without a good number of participants falling into the same group for each area of these categories it was seemingly impossible to assess how these important factors may have played a part in the navigation process. It would have been interesting and informative to recruit lower income, non primary English speaking, and racially diverse participants to evaluate their experiences with a child who has ADHD

Implications for Future Research

As this topic has not been researched extensively it will be beneficial to continue exploring the navigation process with a larger, more diverse sample size. The literature suggests a growing epidemic in ADHD diagnoses which participants confirmed. Furthermore, the fact that all participants were suggested to star their children on psychotropic medication as part of their treatment plan confirms how medication is being seen as the favorable intervention. Future researchers should take this idea and use face to face interviews to produce more data. It would also be informative to include interviews with schools, clinicians, doctors, and the children themselves to compare and contrast how each feels about this process. Exploring the feelings of relief vs. confusion/uncertainty would also be helpful in understanding how emotions play into this process for the parents deciding on treatment interventions and who to ask for assistance. Finally, researchers should look further into treatment sequencing and revisiting past decisions as these areas are limited in past studies.

Conclusion

The question this research was designed to answer was: How do parents/guardians decide whether or not to medicate their child diagnosed with ADHD? The findings of this research show that, while some common themes emerge, all parents have a different experience depending on their child, schools, clinicians, etc. The most pivotal piece of data collected from this study is that all parents reported their child was suggested to start on psychotropic medication regardless of what else had or had not been tried previously. There is still not one single method that is proven effective for all children as each will need a different treatment plan. Even with a small sample size, one can learn from this study the importance of focusing on the individual child's needs as opposed to what may or may not work for other children. There is still a ways to go in researching the topic of ADHD, but the initial stage from the moment it is diagnosed to deciding upon a treatment plan is vital for all involved to understand how to best navigate this process

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APPENDIX A: INFORMED CONSENT FROM

Consent to Participate in a Research Study



SMITH COLLEGE

Smith College School for Social Work • Northampton, MA

.....

Title of Study: Medicating Attention-Deficit/Hyperactivity Disorder in Children and Adolescent: How do Parent/Guardians Decide?

Investigator(s): Michael Schneider, Smith School for Social Work, XXX-XXX-XXXX

.....

About the Researcher:

My name is Mike Schneider and I am a graduate student at Smith College School for Social Work. My thesis project deals with ADHD and the lack of research done on the experience that parents/guardians have while navigating through this confusing and often frustrating process with schools, doctors, and their children. My thesis question is how parents/guardians reach the decision about whether or not to start their child diagnosed with ADHD on medication. I believe that this study is extremely relevant in today’s world because ADHD diagnoses and treatment options can be complicated and frustrating for parents and children and the results could potentially shape how clinicians and families explore and pick out the best option for their child. This survey is your chance as a parent/guardian to express your own experience and potentially help shape how I and clinicians who read my work engage with ADHD clients and their families in the future.

Introduction

You are being asked to participate in a research study to further understand how parents/guardians arrive at the decision whether or not to use medication in the treatment of their child diagnosed with ADHD. Participants are parents/guardians who have children that were

diagnosed with ADHD. If there are any questions regarding this study after you have read this form in its entirety, please email me at mjschneider@smith.edu.

Purpose of Study

The purpose of this study is to understand how parents/guardians make the decision whether or not to medicate a child diagnosed with ADHD. It is the hope that doing so will inform how clinicians and psychiatrists talk with clients about treatment decisions.

Description of the Study Procedures

If you agree to be in this study, you will be asked to do the following things: Partake in an online survey via the Survey Monkey website. This survey will take between 30 and 60 minutes to complete.

Risks/Discomforts of Being in this Study

This study is not intended to change any current decision and does not encourage or endorse making any changes based solely upon completion of the survey. That being said, there is potential for you to rethink and possibly change any current treatment plans you are using for your child. If these thoughts arise, you are encouraged to speak with ((please make first person and use direct language your support system, which may include doctors, friends, and/or family members, and explore (their) feelings related to the current treatment plan and other possibilities that might make you more comfortable.

Benefits of Being in the Study

This is your opportunity to get your voice heard about how you as parents/guardians feel about the process of making treatment decisions for your child. It is my hope that this research will be disseminated to clinicians and positively impact the process for future families.

Confidentiality

The records of this study will be kept strictly confidential. Research records will be kept in a locked file and all electronic information will be coded and secured using a password protected file. We will not include any information in any report we may publish that would make it possible to identify you. The data will be kept for at least three years according to Federal regulations. They may be kept longer if still needed for research. After the three years, or whenever the data are no longer being used, all data will be destroyed.

Payments

You will not receive any monetary compensation for your participation.

Right to Refuse or Withdraw

The decision to participate in this study is entirely up to you. You may refuse to take part in the study *at any time* before completion without affecting your relationship with the researchers of this study or Smith College. Once completed and submitted your responses will be final and unable to be excluded. Your decision to refuse will not result in any loss of benefits (including access to services) to which you are otherwise entitled. If you choose to withdraw, the researcher will not use any of your information collected for this study.

Right to Ask Questions and Report Concerns

You have the right to ask questions about this research study and to have those questions answered by me before, during, or after the research. If you have any further questions about the study, at any time feel free to contact me, Mike Schneider at mjschneider@smith.edu or by telephone at XXX-XXX-XXXX. If you like, a summary of the results of the study will be sent to you. If you have any other concerns about your rights as a research participant, or if you have any problems as a result of your participation, you may contact the Chair of the Smith College School for Social Work Human Subjects Committee at (413) 585-7974. The following is a list of websites that offer further information into ADHD:

CHADD (Children and Adults with Attention-Deficit/Hyperactivity Disorder)

www.chadd.org

ADDA (Attention Deficit Disorder Association)

www.add.org

National Resource Center on AD/HD

www.help4adhd.org

Consent

Your typed name below indicates that you have decided to volunteer as a research participant for this study, and that you have read and understood the information provided above.

.....

Name of Participant (Typed): _____ Date: _____

.....

APPENDIX B: QUESTIONS LIST

ADHD Psychotropic Medication Survey Questions

Qualifying Question:

Do you have a child that has been diagnosed with ADHD?

Demographics

What is your gender?

What is your age?

What, if any, religion do you identify with?

How do you identify your race?

What is your approximate annual household income?

What is your primary language?

What is the highest level of education you have completed?

What is the gender of your child that was diagnosed with ADHD?

Survey Questions:

1. At what age was your child diagnosed with ADHD?
2. What were the circumstances that led to your child's diagnosis?
3. How did you feel about the diagnosis?
4. From your perspective what, if any, behavioral or academic challenges did your child have at the time of diagnosis?
5. From the perspective of others (Primary Care Physician, Teachers, counselors, etc.) what, if any, behavioral or academic challenges did your child have at the time of diagnosis?

6. List in chronological order what you tried to manage these challenges? What was the result of each attempt?
7. Was it suggested that your child be put on medication to help with ADHD symptoms? If so, who made the suggestion?
8. If recommended did you start your child on ADHD medication? Why or why not?
9. If not recommended did you start your child on ADHD medication? Why or why not?
10. If you were starting over right from the diagnosis would you do everything the same? If not, what would you do differently?
11. Overall, what do you feel is the most effective measure taken in the treatment of your child relating to their ADHD diagnosis?
12. Is there any other question that you wished I asked in this survey?
13. Is there anything else you think I should know or would like me to know?

APPENDIX C: RECRUITMENT EMAIL

Hello,

I am sending out this email to recruit participants for my thesis project for my Social Work Master's program. My thesis topic is about how parents/guardians reach the decision on whether or not to start their child diagnosed with ADHD on medication. I believe that this study is extremely relevant in today's world and that by having first hand responses the results could potentially shape how schools, therapists, clinicians, and families explore treatment options. I am asking parents/guardians who have a child that was diagnosed with ADHD to take an anonymous survey lasting 30-60 minutes depending on length of answers. Participants must be self-reported parents/guardians of a child with ADHD. Furthermore, no one will be excluded from participating due to sociocultural differences as comparing these differences is an area of focus for this study. The aim is to have a diverse group of participants by recruiting from different populations across the country.

If you fit the criteria you are eligible to take this survey. If you know of others that fit the criteria, please feel free to forward this email to them. The survey will be on SurveyMonkey.com and I have included the link to the survey (will be included once up and running) in this email. You simply need to click on the link, consent to participating in the survey, fill out the questions, and click submit when finished. The survey itself starts with a consent page that explains everything a participant needs to know before taking this survey. Thank you in advance for taking the time to participate in my thesis study, it is truly appreciated. Feel free to email back with any questions/concerns at mjschneider@smith.edu.

Message forwarded by personal contacts to non-personal contacts:

Hello,

My name is Mike Schneider and I am a graduate student at Smith College School for Social Work. I am currently working on my thesis study and am looking to recruit participants to complete an online survey. My thesis topic is about how parents/guardians reach the decision on whether or not to start their child diagnosed with ADHD on medication. I believe that this study is extremely relevant in today's world and that by having first hand responses the results could potentially shape how clinicians and families explore treatment options. I am asking parents/guardians who have a child that was diagnosed with ADHD to take an anonymous survey lasting 30-60 minutes depending on length of answers. Participants must be self-reported parents/guardians of a child with ADHD. Furthermore, no one will be excluded from

participating due to sociocultural differences as comparing these differences is an area of focus for this study. The aim is to have a diverse group of participants by recruiting from different populations across the country.

If you fit the criteria you are eligible to take this survey. If you know of others that fit the criteria, please feel free to forward this email to them. The survey will be on SurveyMonkey.com and I have included the link to the survey (will be included once up and running) in this email. You simply need to click on the link, consent to participating in the survey, fill out the questions, and click submit when finished. The survey itself starts with a consent page that explains everything a participant needs to know before taking this survey. Thank you in advance for taking the time to participate in my thesis study, it is truly appreciated. Feel free to email back with any questions/concerns at mjschneider@smith.edu.

APPENDIX D: HUMAN SUBJECT REVIEW APPROVAL LETTER



School for Social Work
Smith College
Northampton, Massachusetts 01063
T (413) 585-7950 F (413) 585-7994

February 5, 2014

Michael Schneider

Dear Mike,

You did a nice job on your revisions. Your project is now approved by the Human Subjects Review Committee.

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain all data and other documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms, or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Congratulations and our best wishes on your interesting study.
Sincerely,

Elaine Kersten, Ed.D.

A handwritten signature in black ink, appearing to read 'Elaine Kersten'.

Co-Chair, Human Subjects Review Committee

CC: Hannah Karpman, Research Advisor

FIGURES:

Table 1. Selected Socio-Demographic Characteristics of the Sample (N=26)

| Background Characteristics | Percent (rounded) |
|-------------------------------------|-------------------|
| Gender of Participant | |
| Male | 34.6 |
| Female | 65.4 |
| Age | |
| <35 or >64 | 11.4 |
| 35-44 | 23.1 |
| 45-54 | 30.6 |
| 55-64 | 34.6 |
| Religion | |
| Protestantism | 15.4 |
| Catholicism | 19.2 |
| Christianity | 11.4 |
| Judaism | 42.3 |
| Islam | 0.0 |
| Buddhism | 11.4 |
| Hinduism | 0.0 |
| Native American | 0.0 |
| Inter/Non-Denominational | 0.0 |
| No Religion | 7.7 |
| Race | |
| White | 84.5 |
| Black or African American | 7.7 |
| American Indian or Alaskan Native | 0.0 |
| Narrative Hawaiian/Pacific Islander | 0.0 |
| From Multiple Races | 0.0 |
| Other (Asian, Hispanic) | 7.7 |
| Annual Household Income | |
| \$0-49,999 | 11.4 |
| \$50,000-99,999 | 19.2 |
| \$100,000-149,999 | 34.6 |
| \$150,000-200,000 | 26.9 |
| \$200,000 and up | 7.7 |
| Primary Language | |
| English | 100.0 |
| Spanish | 0.0 |
| Chinese | 0.0 |
| Portuguese | 0.0 |
| Vietnamese | 0.0 |

| | |
|---|------|
| French | 0.0 |
| Other | 0.0 |
| Highest Level of Education Completed | |
| Some High School | 0.0 |
| Graduated From High School | 7.7 |
| Some College | 19.2 |
| Graduated From College | 30.1 |
| Some Graduate School | 15.4 |
| Completed Graduate School | 26.9 |
| Gender of Child with ADHD Diagnosis | |
| Male | 65.4 |
| Female | 34.6 |
| Other | 0.0 |
| Age of Diagnosis | |
| 4-6 | 11.4 |
| 7-8 | 50.0 |
| 9-10 | 15.4 |
| 11-12 | 7.7 |
| 13-14 | 15.4 |