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THE IMPACT OF PARENTS' MEDICATION BELIEFS ON ADHD MANAGEMENT

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ABSTRACT

Adherence behaviour to medication for attention deficit hyperactivity disorder (ADHD) is frequently suboptimal. Parents have several beliefs and experiences about ADHD medication and they going to make their decisions based on that background. This study aims to investigate qualitatively the parental experiences regarding using medication of ADHD for their children with ADHD. A qualitative approach was chosen to gain an in-depth insight into the experiences and beliefs. The investigations approached more than 60 parents during their follow-up. And the final sample included 44 parents. Parents generally were reluctant to medicate their children. Some parents revealed positive experiences about ADHD's medication, mainly when that medication associated with positive performance at their schools. Parents described their hesitancy to continue the medication as a result of having uncertain assessments, side-effects of that medication and stigma. It was rare to hear from parents that behavioural or educational intervention could be used to manage ADHD, mainly when they decide to discontinue medication. There is a need to develop intervention program that educate, encourage, and support parents in following behaviour and pharmacological recommendations.

Keywords: Adherence behavior, Attention-deficit hyperactive disorder, ADHD, Medication, Saudi Arabia.

INTRODUCTION

Attention-Deficit Hyperactivity Disorder (ADHD) is one of the most prevalent developmental disorders, affecting 3–5% of school-aged children [1]. In Saudi Arabia, the prevalence rates of ADHD among school-aged children have varied from 2% to 20% [2], with high ADHD comorbidity such as lower social functioning, learning difficulties, oppositional defiant disorder [3]. ADHD is considered a chronic disorder with a substantial lifelong impact on personal and social functioning, academic performance, and the health features in general. Various intervention such as medication, behavior intervention, counseling and educational intervention could be used to manage symptoms [4]. Despite that medication is not recommended as a first-line treatment in all school age children and young people with ADHD [5], frequently the first line medication in the psychopharmacological treatment is stimulants [6]. Using medication for ADHD can decrease the severity of that disruptive behavior and some behavioral problems, consequently permitting children to involve more effectively with those around them. On the other hand, the clinical database reported that about half of those who start medication treatment discontinue it within a year [7]. Likewise, adherence behavior to ADHD medication has been reported to be failed over the time, irrespective of dosing or form of supportive services [8]. Non-adherence behavior to ADHD medication in the long term is identified as a significant limitation [9]. Health professionals are aware of the importance of adherence behavior in reaching optimal therapeutic outcomes [5]. Adherence behavior has been defined as the key moderator between medical professionals and patient outcomes [10].

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Some studies describe how beliefs about treatment can be a significant predictor of adherence to that treatment [11]. A recent study reported that the rate of non-adherence behavior for ADHD medication range from 13 % to 64% [12].

It is essential for a health professional to understand the beliefs that contribute to non-adherence behaviour to help patients and their family to increase their ADHD management. Understanding why parents of children diagnosed with ADHD leave that medication which was recommended need to be investigated. Although much attention has been paid in Saudi Arabia to the prevalence of ADHD, less attention has been paid to parental experiences regarding using medication of ADHD. There is not yet any information about the stimulant medication of ADHD and the related behaviour and experiences among parents of children with ADHD in Saudi Arabia.

Aim of the study

This study is drawn from a larger investigation project which aims to understand the beliefs of parents of children with ADHD and the impact of these beliefs on the plan and adherence of the ADHD intervention. The current aim of this paper is to investigate qualitatively the parental experiences regarding using medication of ADHD for their children with ADHD.

The qualitative research methods were selected because our objectives were exploratory and hypothesis emerging [13]. Qualitative methods provided a better understanding of the particular experiences about ADHD medication, rather than what could be captured with standardized instruments.

Sample

A cross-sectional survey of parents from urban, rural, and suburban areas of Saudi Arabia were selected. Parents were identified through their children whom had been diagnosed by professionals as well as prescribed medication.

All children were diagnosed with ADHD by Diagnostic and Statistical Manual, Fourth edition (DSM-IV). The parents who agreed to be involved in the study were recruited as per inclusion criteria. The inclusion criteria were the following: a) parents who have a child with confirmed ADHD, irrespective of the type of ADHD and its severity; b) child age between 6 to 16 years. Whereas the exclusion criteria were the following: a) children who had other medical conditions that required on-going medical intervention were excluded.

Sampling was continued until the data became repetitive and no new themes emerged and that saturation of main themes had been confirmed. Through around five years (September, 2010 to May 2014), the investigations approached more than 60 parents. Some parents refused to participate in this study. Discomfort about discussing ADHD medication of their children was the main reason to refuse. A sample of 44 parents of children with ADHD was finally included. The mean duration of interviews administration was 40 minute, ranged from 30 minute up to 60 minute. Volunteering parents were informed that these interviews are not related to their treatment program and that they have the right to choose whether or not to contribute. Confidentiality was assured.

METHODS AND DATA COLLECTION

A qualitative approach was chosen to gain an in-depth insight into the experiences and beliefs. Qualitative research is the ideal method when the objectives are exploratory, and the hypothesis emerging [13].

The semi-structured interview was designed to investigate parental experiences and beliefs through open-ended questions. A set of prompting questions that prompt discussion were designed as well. The interview topics guide (Table 1) was elicited to include beliefs about ADHD treatments. These topics were formed through literature reviews, preliminary discussions with parents of children with ADHD, and advisory panel which included neurologists, paediatricians and neuropsychologists. Any related statement was reported, verbatim, by the interviewers, as well as registering non-verbal communication. Most of the interviews were conducted by the main author, but few were undertaken by trained female psychologists at the request of parents.

Analysis of interview transcripts

During the process of building the preliminary categories, an initial list of key themes were noted and the perceived responses were shaped for the possible categories. The method of analysing data was inductive. In this initial reading, classifying individual responses by preliminary categories were not concerned. Clusters of themes were reported and sought in later reading for confirmation or rejection. Any identification features related to the parents or their children were changed. Then experienced researchers in qualitative studies were advised. They were asked whether the themes made sense and whether interviews had any further themes. The initial themes category was compared with the remaining interviews and was verified by the experts who merged and compound some sub-themes. The saturation method was reported, where no new themes being identified. Quotes were selected to represent and summarize the parent's point of views and to illustrate the variety of beliefs expressed.

RESULTS

The final sample included 44 parents. Age of the parents ranged from 25 up to 53 years. The majority of the parents 75% were between 28 and 42 years of age. Half of the parents (50%) were highly educated, including 11% holding a master's degree or other postgraduate degrees.

Most parents 81% were married and in a stable relationship. About 18% were divorced and 1% is widow. Table 2 shows the frequencies and percentages of the sample. In general, the majority of participants were mothers alone 47.7 %, fathers alone were 15.9% and both fathers and mothers were 36.4%.

Accepting medication

Parents generally began with complex interactions between experiences about ADHD. They were reluctant to medicate their children in general. But some of them described this medication as necessary to avoid the severe symptoms. Some parents revealed positive experiences about ADHD's medication, mainly when that medication associated with positive performance at their schools.

"... Without this medication our son would not be accepted in his school…"P16

For those parents whose children are on ADHD's medication at the time of this study (34.1 %), they were confident that their decision about using medication is right. They were satisfied about that improvement which linked with using medication.

"...he has not had any of that side effect of the medication… I am satisfied with this medication…"P9

It seems that accepting ADHD's medication depend on parents opinion about the medication rather than the severity of the ADHD' symptoms.

"...we think that our doctor knows better than us and he knows well that medicate our daughter is the best way to cure her…. despite that he [Doctor] said that her symptom is mild…"P35

Interestingly, mothers whose children are on ADHD's medication at the time of this study reported positive experiences. Their opinions showed benefits in school achievement and in social lives as well, while fathers reported the improvement in school performance alone:

"...from my opinion as a mother, social interactions are problematic, you now our culture here…social behavior and social interaction are essential skills for children…our child has worthwhile benefits from this medication…we are in something like a dram…we are able now to attend our social activities..."P41

Sometime parents accepted the medication not because of the school achievements requests, but due to social demands.

"...with our kid, the good-day will be largely determined by how visible ADHD was to other family members…"P3

Discontinue medication

Some parents revealed their opinion that medication was being used for one main reason which link to have better school achievement. There were possibilities to suspend medication when parents think that it will not help them in school.

"...we used medications for ADHD when we thought that it could help our child to concentrate better or sit still at his school…. but the benefit was not obvious, then we decided to suspend using medication" P38

Having some information that ADHD's medications have side effects was one major source to discontinue medication:

"...we used this medication for short time, but we realized that this medication has chemical effect in the brain and the nerves system of our daughter…"P13

Some parents blame doctors for not informing them about the possible side effects of that medication:

"...doctors told us about the benefits only of using ADHD's medication…but not the whole picture…then we stop the medication…"P26

Stigma was one main barrier here to continue medication. Parents described their hesitancy to continue the medication as a result of stigma.

"...this is not an ordinary medication, you know, this is a psychiatric medication…people will label our daughter as mental patient….they will think that she has mental illness…"P22

Refusing medication

Parents had made their decision to reject medication based on several backgrounds. One common reason is refusing the ADHD as syndrome:

"...I frequently say she doesn't have anything. She might have a few odd imaginations… sometime she has low concentration in her classroom, but other than that she is fine… when I was a child I was like her… nobody said that I have ADHD"P31

One parent said:

"... is seeing healthy child or active child means ADHD? or abnormal?... the abnormal is when we ask this child to sit silently in his classroom work alone and ask him to ignore other things around him….he is a child… normal child is active and unorganized, uncontrolled and he will be happy for that…".P7

Assessment of ADHD was uncertain for the majority of the parents. Parents repeatedly stressed concerns about ADHD assessments:

"...You know, we see our child as normal. I don't have another certain ADHD criteria to compare ... all ADHD assessments are uncertain"P19

Another parent said:

"...I'm not opposed to ADHD's medication per se, I'm opposed to the ADHD assessments…. It is insufficient".P33

What could be diagnosed as ADHD for professionals seems to be seen as a gifted-child according to parental criteria.

"...as a parent we generally characterized the hyperactive kid as healthy and maybe as smart, but doctors say this is an illness, I am not sure about their opinion…without having medical analysis…. not assessments, I will not accept this assessment" P2

Some parents blame teachers and schools. Parents view the ADHD diagnosis as caused by teachers who try to control the hyperactivity of their children by medications:
".... As you can see… nowadays teachers want to have easy task only…in the past this hyperactivity were controlled by teachers at schools without medication, you knew..."P11

Blaming teachers for causing that diagnosis is not only for the hyperactivity disorder, but also for having the attention deficit.
"… teacher should walks in her students' shoes… if she[teacher] mind that one of her students is behind his peers a bit she needs to stop to encourage hem to pay more attention… it is part from here duty as a teacher.... it is not the duty of our clinics or doctors…"P23

Complementary and alternative medicine:
It was rare to hear from parents that they have clear idea about the behaviour intervention or about any psychological or educational intervention as an intervention for ADHD, mainly with their decision to discontinue medication.
"…doctor has nothing to offer, only medication…and teacher refers us to doctor…no educational program… I hear nothing about behavior program…"P43
It is worth noting that frequently parents revealed their attracted to try expensive interventions using various uncertain interventions such as electronic devices.
"…they informed me and my husband that this electronic device is intended to reduces distractibility and will increase our daughter attention without drugs….it is expensive and need long-term plan of intervention".P8

Table 1. The interview guide questions and prompting questions

Guide questions	Prompting questions

• Description of symptoms and signs of your child ADHD.
  ○ In a few words, could you tell me about your child's problems?
  ○ Could you please describe a typical case history of your child?
• Impact of ADHD on family:
  ○ At home.
  ○ At social activities.
  ○ Other.
• How does parent know that ADHD' medication is well controlled symptoms or not?
  ○ How does parent know that ADHD is well controlled or not by medication?
• Medication effects on your child's life
  ○ Home.
  ○ School
  ○ Social.
  ○ Others
• Explanation of child's ADHD symptoms with/without medication.
  ○ Home.
  ○ School
  ○ Social.
  ○ Others
• What makes your child ADHD get more ill/less ill?
  ○ Medication
  ○ Education
  ○ Behavior.
	*Probes*1:
	• How these medications effect your child's symptoms?
	• How could this medication cure your child's symptoms?
	• Why do you think this medication could help/not help your child's problem?
	• Did your doctor inform you about this medication?
	• What do you think about medication?
	• Who is with your choice about your child' medication?
	• Who is not with your choice about your child' medication?
	Probes2:
	• Have you used any alternative medication/helps to cure your child' ADHD?
	• What was your experience in using this medication?
	• What was your experience in refusing this medication?
	• What information about this medication that could be missing here and you need/needed?

Table 2. shows the frequencies and percentages of the sample

Characteristic		Frequencies	%
Sex	Boys	27	61.4
	Girls	17	38.6
Age	6-9	21	47.7
	10-13	16	36.4
	14-18	7	15.9
Age at diagnosis	2-4	31	70.5
	5-7	11	25.0
	Above	2	4.5
ADHD subtypes	Hyperactivity	23	52.3
	Attention	14	31.8
	Combined	7	15.9
ADHD comorbidity	Learning disorder	28	63.6
	Lower social functioning	37	84.1
	Oppositional defiant disorder	22	50.0
ADHD's medication was prescribed	Yes	44	100
	No	0	0
On ADHD' medication at the time of this study OR before	Yes	15	34.1
	Was	17	38.6
	No	12	27.3
Parents Age	25-33	15	34.1
	34-42	18	40.9
	43-53	11	25.0
Parent's Education	Primary	9	20.5
	Secondary	13	29.5
	Higher	22	50.0
Parent's marital status	Married	36	81.8
	Separated, divorced , widowed	8	18.2
Residence	Urban	31	70.5
	Semi-rural	8	18.2
	Rural	5	11.3

DISCUSSION

About two-thirds of our sample had been in medications, half of them were on medication at the time of this study. This could give the sample the impact of having enough experience about ADHD. It should be mentioned that this sample shows varying lengths of time of using medication, from just starting the medication to having used medication for years. Interestingly, and as it has been reported in previous study [14], the transcripts revealed similar themes throughout parents' interviews.

Parents frequently spend hard time to decide whether to use medication for AHHD or not. Previous studies reported that parent move through several stages before making the decision to medicate children [15].

Parents' beliefs about ADHD medication exist in the social context with complicated views about psychiatric conceptualizations of children's psychological health, and about behavioural difficulties related to the ADHD in particular [16].

Using medication with ADHD, has been extensively studied and commonly provides significant short-term improvement, mainly academic improvement [17; 18]. The current results show that more than one-third of the sample discontinues medication. Several studies reported that nearly half of diagnosed children with ADHD who do begin medication suspend it within a year [7].

Although professionals practice ADHD-guidelines that promote the use of Pharmacotherapy, parents could have reservations attitude about using medication [19].

Some parents could see the ADHD's medication as the last choice. Other parents could wait looking for

another choice. But in some cases medication could be prescribed when alternative treatment exist and has not been used yet [17]. This complex situation may show the gap between parents and doctors and how this influence medication use. Understanding this scenario and work to bridge this gap is essential.

According to previous studies, medications should be used only for those children who not responding sufficiently to behaviour and educational interventions [20]. Frequently, it has been reported that mild to moderate symptoms of ADHD do well at home and school without medication using behaviour, psychological and educational interventions [21]. On the other hand, children with more severe symptoms benefit greatly from medication.

It has been reported that behavioural problems are rarely completed treated by pharmacotherapy intervention [15]. Therefore, combined treatments of pharmacotherapy and behaviour therapy are increasingly described as the treatment of choice for ADHD [22]. Virtually all investigations of combined treatments which have involved pharmacotherapy and behaviour therapy did not exist among parents' experiences throughout all of interviews in the current study. Such interventions require clinical psychologist who has sufficient training in in behaviour therapy which is not accessible to most of our clinics in Saudi Arabia.

Similar to previous studies [23], stigma could play a major part here. Stigmatizing beliefs about individuals with ADHD could have created a "culture of suspicion" about ADHD' medication, especially when such medication involves a child [24]. It has been reported in previous study that children who receive mental health treatment are stigmatized [25]. By contrast, mental health medication adherence was associated frequently with lower perceived stigma [26].

Parent may get much of their information from the internet rather than from those scientific inaccessible materials [19]. Unfortunately, parents repeatedly are enticed by social media information to try numerous interventions with no scientifically proven benefit. There are various alternative therapies that claim to help children who have ADHD. Without education parents, the proper intervention could be missed. It is essential that health professionals be aware about these different beliefs and provides a proper educational program to adapt the knowledge and beliefs scientifically and suggest the evidence-based interventions [27].

CONCLUSIONS

The conclusion show poor medication adherence. It seems that this is a result of that clear gap between professionals and parents in their beliefs about ADHD medication. Closing this gap is essential given the known negative outcomes associated with untreated ADHD. Medication plays a main role in the intervention of those children with severe impairment. Combined treatments of pharmacotherapy and behaviour therapy is recommended for all cases, but also should be provided to those children who not responding satisfactorily to medication and also when parents' decision is to reject medication. Heath professionals should provide opportunity for open discussion with parents to clarify any concern or misconception about ADHD. Finally, there is a need to develop intervention program that educate, encourage, and support parents in following behaviour, psychological and pharmacological recommendations.

LIMITATIONS AND IMPLICATIONS FOR FUTURE RESEARCH

This qualitative study produced a unique sight into the personal journeys of the parents of children diagnosed with ADHD. Understanding why parents of children diagnosed with ADHD discontinue medication requires further quantitative study.

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