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Difficulties in Recognizing ADHD in an Urban Population and Treatment Satisfaction with a Short and a Long Acting Stimulant

Antigone Papavasiliou, Irene Nikaina, Anna Spyridonidou and Eleanna Nianiou

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1. Introduction

Attention deficit hyperactivity disorder (ADHD) is an established neuropsychiatric disorder in children and adolescents with paediatric or mental health services available across most of Europe. In spite of major improvements in the availability of services for the diagnosis of ADHD and several therapeutic options, including medications, psychosocial and psychoeducational therapies, families of children with ADHD experience considerable emotional and social burden [1-2]. The presence and severity of the child's ADHD is a significant predictor of heightened parental stress and the diagnosis of ADHD can result in impairments in the Quality of Life in patients and their families [3-4]. Yet, there is a rather limited number of studies exploring parental perceptions of the diagnosis and overall treatment of this disorder.

An American study determined that primary care physicians generally adhere to practices specified in the AAP guidelines [1] for the diagnosis and treatment of pediatric ADHD; some variations existed and improvements were possible. Poor access to mental health services, limited insurance coverage, and other potential system barriers to the delivery of ADHD care were noted [5]. An Australian study explored perceptions relating to the diagnosis, treatment and overall management of the disorder [6] in the families of 278 children with ADHD identified in a community sample of 11 184 children aged 10-12 years; only 66% of parents recalled the use of questionnaires or rating scales, drugs were tried in 82% and 66% of the children were still on them, behavioral intervention in 42% and alternative treatments, mostly elimination diet and/or fatty acid supplementation, were used in 71%. Overall, 55% of parents were satisfied or very satisfied with their child's care. The conclusion of this study was that adherence to recommended diagnostic guidelines was inadequate, behavioral intervention



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was underutilized and non-conventional therapies were widely used and considered helpful in one-third of the children who used them. A study conducted on 20 low socioeconomic status mothers with children 5-11 years of age with ADHD taking stimulants, aimed to examine the effect of a 5-week educational intervention on ADHD [7]. Parental satisfaction and parental sense of competency improved in mothers who participated in the educational intervention.

Psychosocial and psycho-educational interventions as well as pharmacological treatments are effective in reducing ADHD symptom frequency and severity [1]. Stimulant medications are recommended as a first-line modality for treating ADHD [8]. They proved effective in improving both ADHD core symptoms (inattention, hyperactivity and impulsivity) and the behavioral problems that frequently accompany the disorder (such as aggressive behavior, depressive mood, anxiety, tics, impaired social functioning and academic productivity) [9]. Remission of ADHD symptoms via medication provides the best possible chance for educational and social re-integration and improved functioning through the utilization of nonpharmacological interventions [10]. Methylphenidate (MPH), a stimulant, is available in immediate and extended release forms. Because the half-life of MPH in immediate-release formulations is short, twice or better thrice daily administration is needed in order to maintain the desirable therapeutic effect. This obviously creates many practical difficulties during school days; it affects the patient's emotions (embarrassment in taking medication at school), it interferes with medical privacy preservation, and contributes to poor compliance with the therapeutic regimen [10-11]. Once-daily MPH in extended release form is significantly more effective than short acting MPH based on multiple outcome measures including remission rate [10,12], with better compliance being a primary factor [13-16].

Satisfaction with medication or any therapeutic intervention is an important factor in the evaluation of overall treatment outcome in ADHD or any other disorder; it is predictive of better adherence and compliance to treatment, and prevents premature treatment termination [17]. It depends primarily on the effectiveness of the drug but it is also influenced by parental and patient expectations, demographic characteristics, social acceptability of the treatment, the relationship between patient/parents and physician as well as the physician's knowledge, competence and ability to communicate with patients and their families [18]. Cultural factors are also very important in the acceptability of the treatment [19]. Furthermore, use of stimulant medication combined with frequent reviews (at least 6 monthly) was more likely to be associated with overall management satisfaction [6].

The goals of this paper were a. to explore family experiences in seeking diagnosis and treatment of ADHD in an urban community and b. to investigate acceptance and compliance of stimulant medication and specifically the two preparations of MPH available in our country, one in immediate and one in extended-release form (Ritalin and Concerta).

2. Patients and methods

Two independent samples of children fulfilling DSM-IV criteria for ADHD and their families were recruited to test the study goals. Diagnosis was based on the clinical presentation of the child and on specific standardized diagnostic tools and was established by a specialized group of physicians (pediatrician, pediatric neurologist, pediatric psychiatrist), school and clinic

psychologist and special educator. Relevant patient characteristics such as demographic characteristics (age, sex), ADHD type, previous treatments, concomitant disorders, along with information on the prescribed treatment were recorded.

Study group 1. Thirty three families with children who fulfilled DSM-IV criteria for ADHD, 5-16 years old, who consecutively visited our outpatient department for the first time received an open ended questionnaire, consisting of 6 main questions and 12 sub-questions that investigated family impressions and experience in dealing with this disorder. More specifically, we asked about a. reasons for seeking help, b. source of referral (self-referred, schools, special educators, physicians, psychologists), c. obstacles they confronted in reaching diagnosis and treatment (difficulty in reaching specialized care, difficulty in dealing with education problems). A DSM-IV derived inattention/hyperactivity scale was used in order for parents to rate their children for 18 DSM-IV category A symptoms, on a 4-point scale [20]. This form was used in the follow up visits of our patients in order to document response to treatment. Therapeutic options were then offered including the use of short acting MPH, with a dosage schedule that called for 5 mg qam or bid at the onset and dosage titration to less than 2.0 mg/kg/day or 60 mg per day [21]. Patients were also offered a psychotherapeutic program focusing in social capabilities practice. Their parents were involved in counseling sessions and were encouraged to participate in support and advice groups, aiming at strengthening the net of care around the patients. Other treatment options were speech therapy, occupational therapy and special education as needed per individual child. The therapy that was actually used as well as the efficacy of the medication was subsequently explored by a different physician 6 months after the initial visit. The safety of the prescribed medication was also explored at that time.

Study group 2. Eighty four patients \leq 18 years old, who were also followed as outpatients in the Pediatric Neurology Department, were included in the current study group. Inclusion criteria were a. ADHD diagnosis and b. the decision to begin treatment with long acting MPH. Doses were calculated according to body weight with the final dose less than 2.0 mg/kg/day or 72 mg/day [21]. All patients had been also offered psychosocial and psychoeducational intervention programs and their parents were involved in counseling sessions as well as support and advice groups. Previous treatment with short acting MPH was not an exclusion criterion in this study.

Six months after treatment initiation, a telephone interview was scheduled by a physician other than the one who prescribed the treatment, in order to determine their satisfaction level from the newly introduced treatment. A four level Likert scale was used for this purpose (0= no satisfaction at all, 1=modest satisfaction, 2=moderate satisfaction, 4=great satisfaction) and free comments on their impressions were encouraged and recorded. The safety of the treatment was also explored.

3. Statistical analysis

Continuous variables were tested for normalcy with the Kolmogorov - Smirnov test. Normal variables were then presented as mean values (± standard deviation). Categorical variables were expressed either as percentages or as absolute numbers.

Study group 1. Descriptive statistics based on the parents' answers are reported.

Study group 2. In order to determine the prognostic factors which could affect the satisfaction level from the treatment with long standing methylphenidate a logarithmic regression model was applied with the variable coding the level of satisfaction, used as dependent variable modified to include only two categories (median to great satisfaction versus no to mild satisfaction). As independent variables in the model we used variables coding patients' characteristics (age, sex, ADHD type) and features of the treatment under study (previous treatment with short acting MPH and the response rate to this previous therapy), that may affect the level of satisfaction or that may be important confounding factors. Continuous variables that were introduced in the model were previously centered.

4. Results

Table 1 displays a summary of the characteristics of the two study groups.

Study group 1. The parents of 33 children (20 boys and 13 girls), 6-16 years old (10 years 3 months ± 2 years 10 months) reported the following: a. The reasons reported for seeking help were: 48.5 % increasing difficulties at home and poor school performance, 21.2 % school recommendation, 18.2 % other developmental problem (such as speech delay) and 12.1% parents' concern about child's behavior. b. Only 3% of our patients were referred by their peadiatrician, while 36.3% were self-referred, 27.3% were referred by a state mental health clinic, 21.2% by a psychologist/speech-therapist or occupational therapist, and 12.2% by a school teacher. c. Over half of the 33 families included in this study group had difficulties in reaching specialized help; more specifically, 33.3% encountered ignorance about ADHD-appropriate medical services, 27.3% reported no difficulty, 21.2% encountered lack of appropriate medical services, 12.1%, large waiting lists in hospitals and mental health services and 6.1%, other problems. Almost 50% of them reported ignorance and unwillingness on the part of school teachers to provide help with their children: 45.5 % of the school teachers were ignorant and not helpful, 30.5 % were ignorant but helpful and supportive to the child in the classroom and only 24 % were informed and helpful.

As for their impressions about the disorder, parents' considerations about the cause of ADHD were as follows: 30.3% reported ignorance, 24.3% believed that there was inheritance, 21.2% attributed it to a complication in pregnancy-delivery, 15.2%, to problems in school / family environment, 6%, to some psychological problem and 3%, to a complication due to a disease. Treatment with short acting MPH (Ritalin) was proposed to 91% and 79% of this patient population received Ritalin; of them 95% described benefit in attention and behavior (73% reported major improvement in the ADHD core symptoms, 23% reported little but important improvement). Continuation of treatment was accepted by 63%. Reasons for not accepting continuation of methylphenidate were fear of addiction and unspecified side effects. The medicine was well tolerated by the majority of them with only one having to interrupt the treatment because of gastrointestinal symptoms (vomiting). Other side effects (reported by 38% of the parents) were decreased appetite, sleepiness, tics, nervousness and headache.

Study group 2. Eighty four children, 66 boys and 18 girls, with a mean age of 13 years (\pm 3 years) were offered treatment with long standing methylphenidate (Table 1). Thirteen of them stopped prematurely or never started treatment and as consequence they were excluded from the statistics. In the subsequent analysis, 71 children who received treatment were finally included (55 males / 16 girls). According to their initial symptoms patients were categorized into three ADHD types: inattentive type 33,4% (v=23), hyperkinetic/impulsive type 64,8% (v=46) and mixed type 2,8% (v=2). The age at diagnosis was 8 years and 4 months (SD = \pm 3 years 3 months). Mean age at treatment onset was 10 years 8 months (\pm 3 years). Fifty of our patients (70.42%) had been previously treated with short acting MP. However, data about response to that treatment were available for 47 patients; with 34 out of them having responded well to that treatment (27 had a good response and 7 a very good response).

| | Study group1 | Study group 2 |
|--|---|---------------------------------|
| Age | 10 years 3 months \pm 2 years 10 months | 10 years 8 months \pm 3 years |
| Male/female | 20/13 | 55/16 |
| ADHD type (inattention / hyperactive/ combined) | 13/5/15 | 23/46/2 |
| Previous treatment (yes/no) | 0/33 | 50/21 |

 Table 1. Demographic and clinical characteristics of the two study groups

At the time of treatment initiation with the long acting MPH (Concerta), most of our patients (v=47) were given an initial dose of 18 mg, that was subsequently titled to higher doses. A higher initial dose (36 mg) was given to 33 patients (46.48%) who had high body weight. Lowering this initial dose became necessary in only one patient.

Concerning parent satisfaction level, the majority of them (80.28%) reported moderate to full satisfaction, 36.6% moderate satisfaction and 43.7% full satisfaction. The most frequent effect was observed in the attention domain (improvement in 97.18% of the children), followed by the effect in hyperkinetic behaviour (improvement in 63.38% of the children). Impulsivity was not controlled in the majority of the patients (improvement in 19.72% of them). Almost half of the patients reported improvement in two of the ADHD domains (n=34, 47,89%), 12 patients (19,9%) improved in all three domains and only one reported no improvement in any of the domains of the disorder. Thirty eight of the patients previously treated with short acting MPH (80.85%) reported moderate to full satisfaction with the long acting formulation. Only one of the parents who were not satisfied with short acting MPH (n=13) continued to be dissatisfied with the long acting one. Eight patients with good response (2-3) to the short acting MPH, however, were not satisfied with the long-acting MPH.

The logistic regression analysis applied in order to reveal prognostic factors affecting parental satisfaction level showed that only age at treatment initiation with long acting MP was an independent prognostic factor (OR=1.38, 95%CI=1.04 –1.83, p=0.025). Treatment initiation at an older age resulted in higher probability (by 38%) of moderate to full parental satisfaction

from the treatment, with the type of ADHD, sex and the previous treatment with short acting MP treated as confounding factors (p=0,423 p=0,963 and p=0.299, respectively). Similar results were also reported when the analysis was restricted to the subset of patients who were previously treated with the short acting regimen. In this analysis we also examined the response rate to the previous medication as an important prognostic factor. Age at treatment with long acting MPH onset was again the only significant determinant of parental satisfaction (OR= 1.49, 95%CI= 1.05-2.11 p=0.026). ADHD type, sex and response to Ritalin (moderate to full response vs no response to modest response) were not significant covariates (p=0.929, 0.543 and p=0.320, respectively).

5. Discussion

Families of children with ADHD frequently experience considerable emotional and financial stressors [21-23]. These harmful effects of ADHD on patients and families affirm the need for effective treatment and make it a public health concern [24]. Children with ADHD require more than 1.5 times more primary care visits, 9 times more outpatient mental health visits, and 3 times more prescriptions per year, compared to children without ADHD [25]. It was estimated that the total annual health care costs for children with ADHD is more than twice that of children without the disorder, and these costs become significantly larger when a child with ADHD is diagnosed with a comorbid condition [25-27]. It is also noted that the direct cost of treatment for this disorder has increased considerably during the last years. The increase in expenditure for the treatment of ADHD may be due to increasing demand for diagnostic and therapeutic services and improved availability of such services. [28-30].

The first important finding of this study was that only one fourth of the families studied (Study group 1) reported an easy accessibility to appropriate services for the diagnosis and therapy of ADHD in their children. Several barriers to the diagnosis of the disorder have been previously reported. It is interesting to note that, although parents usually realize that something is wrong with their child, especially if symptoms are severe, they are not always seeking medical advice. In 2003, Bussing et al demonstrated that whereas 88% of high risk for ADHD elementary school students were recognized as having a problem, only 39% had been evaluated [31]. Few years later, in 2006, Sayal et al, in another study exploring barriers to the identification of ADHD, found that the main barrier to care for ADHD is the limited presentation of these problems to primary care [32]. Although most of the parents contacted (80%) recognized that their child had a problem, only few had consulted primary care physicians or had sought help from specialist health services while some had been in contact with professionals in educational services. On the other hand, Leslie and coworkers suggested the existence of a pattern of delayed diagnosis, mostly associated with failure to recognize ADHD by parents/ caregivers [33]. This pattern was more common among youths with complicated clinical and/or environmental factors or primarily symptoms of inattention. Delayed diagnosis was reported especially in girls with ADHD, due to the predominance of symptoms of inattention rather than hyperactivity/impulsivity as compared to boys [34-35] and due to the lower frequency of conduct disorder, aggression, or delinquency [35-38]. Parental recognition of problems and their perception of hyperactivity as a symptom of a disorder, rather than a childhood feature, were reported as to the most significant factors influencing contact with medical services [32, 39].

Recognition of the disorder by primary care physicians, though, was related to both child and parent factors (especially the first). Non-recognition of ADHD in the primary care setting was the main barrier to further accessing specialist services [39]; when the parent was unaware or reticent about the possibility of requesting a referral, then the diagnosis could be missed. Therefore, parental request for referral and thus parental recognition of hyperactive behaviour as problematic plays a crucial role in accessing primary care as well as specialist services [39]. Race has been one of the factors contributing to barriers in diagnosis; Caucasian children had twice the odds of being brought to attention than other racial groups, with boys having a 5fold increased possibility of being evaluated [32]. Ethnic minorities had a lower rate of diagnosis and treatment for the disorder. Those racial/ethnic disparities in service use are the result of a combination of access barriers and individual, cultural, and societal factors [40]. After the diagnosis of ADHD was established, Hispanic families used the fewest services, single-mother families used the most of them and families with boys with ADHD used more services as compared to families with girls with ADHD [38]. Surprisingly, economic status of the family was not a stable prognostic factor of accessibility and usage of specialized services. In the study of Kendall et al income was not a significant factor in any services used or services requested, whereas in the study of Bussing et al poverty status was associated with lower treatment rates and with the most pervasive barriers [31, 41].

Another striking finding of this study was that only 3% of patients were referred to specialized care by a pediatrician; this points to the need for better education of paediatricians on ADHD and dissemination of existing knowledge and guidelines on diagnosis and treatment. According to clinicians' perceptions about ADHD, the diagnostic process is considered complicated, time-consuming and experience requiring, while published guidelines were viewed as vague [42]. Referral rate by school teachers was also quite low (approximately 12%); we believe that lack of appropriate education of the teachers on ADHD seems to be the most important factor. In a survey aiming at exploring perceptions of ADHD with a focus on gender differences, many teachers reported that they have received little or no education in ADHD as part of their curriculum (with only 10% of schools providing significant training for teachers on ADHD), while few reported having received significant training [43]. Moreover, half of the interviewed teachers revealed that even when they suspected that a child suffered of ADHD, they hesitated to inform his/hers parent or guardian. The years of experience with hyperactive children, the number of hyperactive pupils in their classrooms, and the level of perceived self-efficacy of the teachers seems to have a positive correlation with their knowledge about ADHD, which is focusing more on symptoms and diagnosis [44]. Lack of educational support and teachers' understanding of ADHD were also identified as problems, in the study of Concannon and Tang [6].

Concerning perceptions about the etiology of ADHD, one third of the parents we contacted had complete ignorance about causes of ADHD, almost 20% believed that environmental and psychological factors had a causal relationship and the remainder attributed the disorder to a

medical condition/disease or to inheritance. Perceptions about ADHD causes have evolved during the recent years in different communities. Almost two decades before, the disorder was attributed to poor diet, antisocial conduct, lack of discipline, emotional problems at school and in interpersonal relations [45]. Yet, even today an impressing reluctance to accept the biomedical explanation of ADHD exists, especially in developing countries. Psychological problems, socio-environmental factors, learning and memory difficulties, inappropriate parenting and disciplinary practices [46-49] continue to be seen as possible causes. Guilt and self-blame, accusations towards the spouse and concerns about the volitional or non-volitional nature of the problem, still, prevail in parents' beliefs. In a study conducted in Greece, parents were more likely to report intentionality in boys with ADHD than in girls whereas biological dysfunction was considered as a more likely etiology in girls than in boys [50].

In this study, we explored attitudes towards ADHD treatment among the families that participated. In the first part of this study, 79% of the parents accepted MPH treatment following medical advice but only 63% finally continued the therapy. The respective percentage of the second study group for treatment initiation/6-month continuation was 84.5%, which is considerably increased compared to the first one; this difference could be attributed to the evolution of time, (study 1 preceded chronologically study 2). Yet, both rates are quite high. Hoare et al, reported that 88.1% of their sample wanted their child to continue treatment more than 21 days (the initial trial period) and 63 % completed the 1-year trial (extension phase) [51]. In contrast, Chen et al reported that approximately 30% of young people received MPH treatment within one year after diagnosis, and virtually none remained in treatment beyond 12 months [52]. Sample study composition may be responsible for the discrepancy among our results and those of Hoare et al in one hand and the results of Chen et al in the other hand. In the study of Chen et al, only newly diagnosed, and thus treatment naive, children were enrolled, whereas in our study more than half of the participants had previously used the short acting MPH regimen and in the study of Hoare and coworkers, all participants had changed from the short to the long acting MPH medication. It is reported that, despite high response rates to the pharmacotherapy (approximately 70% or more when patients were strictly complying with the treatment) [53-55], parents and teachers consider non-pharmacological therapies or the combination of pharmacological and non-pharmacological therapies to be more acceptable [54, 56-59]. Leslie et al suggested three types of parental reactions to medication proposal: a pattern of preference towards non medication treatment as their initial choice; a reluctant receipt of an ADHD diagnosis and/or treatment pattern, mainly seen among the low-income, Spanish-speaking families; and a rapid engagement in medication use pattern, characterized by directed movement to and maintenance of medication use [33].

Treatment decisions in ADHD are usually the result of a shared process between families, children, and the clinician [42]. Parents and clinicians conceptualize ADHD differently and they should negotiate a shared understanding of ADHD. Parents' terms reflected ADHD's effects on the child and family, while clinicians often mentioned school. Treatment discussions should be tailored to encompass families' varied emotional and educational needs [60]. Recognition of a medical etiology for the disorder was the most influential factor reported in willingness to accept drugs and/or combination treatment [58-59]. On the other hand, the main

reasons for hesitating to start medication were concerns about side effects, worries about the stigma associated with ADHD or its treatment and concerns about medication (the belief that the medication would lead to drug addiction in adulthood) [43, 46]. Factors associated with earlier initiation of MPH treatment were older age, sex (with parents of girls being more willing to start medication), lower socioeconomic status, diagnosis of the disorder while school was in session, diagnosis from a physician specializing in pediatrics or psychiatry, and diagnosis in a district hospital/clinic [43, 52]. Patients more severely ill and/or having co-morbidities had also a greater possibility of receiving treatment [61] In a study aiming to evaluate predictors of long-term adherence to treatment with methylphenidate the authors reported that the presence of associated disorders, younger age, female gender, and single-parent families were predictors for continuing medication for 36 months (study duration) [62]. On the contrary, older age, medication concerns, the absence of associated disorders and serious side effects appeared to increase the risk of discontinuation of the treatment or loss to follow up [52, 62, 63, 65]. Generally, ADHD medication adherence and persistence seems to be suboptimal, with patients using non-stimulant medication being more compliant compared to stimulant users. Since ADHD can be effectively treated with medications, health professionals should be proactive in identifying patients with poor adherence and intervene to address barriers to medication adherence and persistence [66]. In this study, the reasons for treatment discontinuation were side effects and fears of addiction to treatment.

Side effects reported in this study included mostly gastrointestinal and central nervous system symptoms. This finding is in accordance with a recent review in which, decrease in appetite, gastrointestinal pain, and headache were considered as the most frequently reported adverse reactions, with very few of them being rated as serious. However, since a large number of children drop out of studies due to serious side effects, it is believed that their actual number is probably higher. These side effects are reported in clinical studies of short duration, whereas long term safety is still a matter of research [69, 71]. Concerns about possible harm, especially, from the newly developed ADHD drugs have arisen, focusing on both minor adverse effects and extremely serious issues such as sudden cardiac death and suicidality [72]. Another important finding in this study was that a great percentage of the ADHD parents expressed at least moderate satisfaction from the long acting MPH. This is not surprising since previous studies had advocated overall medication satisfaction, as expressed by patients, parents/ caregivers and/or physicians. Generally, satisfaction with stimulant medication as the sole therapy has been shown to be relatively high and 63-87% of patients, parents and teachers made positive assessments [11, 64, 69 -70]. In most of these studies, the researchers explored satisfaction rates for long acting MPH as compared to short acting MPH. In a study presented at the 2004 Annual Meeting of the Canadian Academy of Child and Adolescent Psychiatry, on the pharmacological evolutions concerning ADHD, Swanson and Hechtman reported significantly higher remission rates and significantly higher Clinical Global Impression and parent satisfaction scores with long acting MPH as compared to short acting MPH (results from an 8-week open-label trial) [71]. Similar results were presented in 2006, in another 8 week, multicentre, randomized, open-label study in which 147 ADHD patients (6-12 years old) received either once-daily long acting MPH or usual care with the short acting regimen. The first drug proved to be superior to the latter in terms of remission rate, severity of ADHD and ODD symptoms, Clinical Global Impression-Improvement, Parent Satisfaction with treatment (50% of parents were 'completely satisfied' with long acting MPH given once daily, compared with 21% with the short acting MPH given two or three times daily) and other secondary outcome scores [10]. In 2005, Hoare at al, also, reported that in the case of children previously treated with the short acting regimen and then switched to the long lasting one (n=105), the parent/caregiver global assessment of satisfaction ranged from 49 to 69% after an initial 21-day trial, and 49 to 71% of investigators rated the treatment as adequate [51]. Finally, in a double-blind comparison of a long-acting MPH formulation (osmotic release oral system [OROS] MPH [Concerta, Janssen-Cilag Ltd]) given once-daily versus three-times-daily MPH-IR, 47% of parents preferred the long-acting formulation, 31% the IR formulation, and 15% their previous MPH treatment [72].

In this study, the vast majority (~81%) of the patients' subgroup previously treated with the short-acting regimen were at least moderately satisfied. From those parents who reported a good response with the short acting MPH, 26/34 were satisfied with the long acting one and only 8/34 were not. From those exhibiting an inadequate response with the short acting MPH, 12/13 subsequently report moderate to full satisfaction. This is consistent with previous results, according to which, switching from one MPH preparation to another appears to be a valid clinical approach that may contribute to treatment success. Four factors were postulated to be responsible of the observed improvement in various treatment outcomes: first, the increase (and thus optimization) of MPH dose; second, the shorter intervals between visits directly after switching, leading to more intense education and guidance of those involved; third, a positive expectation of improvement by all participants; and fourth, a possible increase in adherence in the long-term [18, 73-74]. On the other hand, dissatisfaction rate does not necessarily reflect low efficiency. In the study of Gortz-Dorten et al, approximately 30% of parents were dissatisfied with the medication, while efficacy was highly rated, making treatment individualization a very important aspect of the pharmacological treatment [18].

In our study, most parents reported satisfaction with the MPH effect especially for inattention symptoms, followed by the satisfaction rate on the hyperkinetic behavior. This high satisfaction rate on the grounds of improvement in attention had also been reported in a recent study, in the school setting and in academic situations [18]. The overall parental satisfaction with the medication exceeded the percentage of 70% (63-75.6%). The parents were also very satisfied with the effects of the drug in the children's social interactions with other children and within the family. Finally, almost 56% of parents also reported high satisfaction with how the medication helped their child feel good. These results are supported by other studies, performed in the UK and in Sweden [70, 75].

Finally, according to our results, age at treatment initiation was a significant determinant of level of parent satisfaction. We were not able though to relate parent satisfaction with type of ADHD, sex of the patient or the previous experience with short acting MPH. In 2005, Hoare et al, exploring the efficacy of long acting MPH in the long term (12 months) reported that efficacy and satisfaction were more common in patients of older age (10-16 years), those on a higher dose (36 mg or 54 mg) and those with the predominantly inattentive ADHD subtype [51], results only partly in aggreement with ours. In another study, parents expressed higher

satisfaction rates if their children showed a greater reduction in ADHD symptoms and greater improvements in all QoL domains [18]. They argued that symptom severity and/or functional impairment at the end of the study, as well as QoL, were the most significant predictors for parent and patient satisfaction. They also showed that satisfaction with medication slightly but significantly increased during the treatment and as time passed (from visit 1 to visit 3).

The results of our study need to be viewed in light of several limitations.

Limitation 1: One major limitation of this study was that parents' satisfaction was assessed by asking parents how satisfied they were, using a Likert scale. At the time of study conduction, there were no standardized and validated rating scales for satisfaction in Greek, not to mention that the whole concept of using such scales was new. The method we used is clearly not consistent or uniform and prevents the conduction of immediately comparable studies [19]. In the literature on ADHD, measures of satisfaction with medication such as the medication satisfaction questionnaire (MSS) [76] or the parent consumer satisfaction questionnaire (PCSQ) [77] exist and these were not used by us. In a recent study, another measure, the satisfaction with medication scale (SAMS) has been validated [18]. This new rating scale was designed to assess the satisfaction with ADHD medication of parents and children on a per item basis. It would be very informative if a new study using these measures is conducted in our setting.

Limitation 2: Satisfaction level in our study was reported only for parents/caregivers. Patient satisfaction with medication though may be an important factor in the evaluation of overall treatment outcome [64]. In order for treatments to be considered effective, they have to be viewed favorably by patients who also have to be willing to use them [19]. Although parental satisfaction is usually in accordance with the child's feeling on treatment effect, this is not always the case. In a double-blind crossover study child and parent perceptions of treatment with stimulant medication in a sample of 102 children with ADHD was attempted; disagreement between child and parental perceptions of treatment response existed in >25%. This involved mostly parental viewing of the child's response favorably, while the child's rating was unfavorable; side-effects were the main determinant of children's perceptions of adverse outcome. Thus, parental report alone is not infallible in providing reliable information regarding effects as experienced by the child [58]. In another study consisting of 79 child-parent peers, few differences between parents and children for positive effects existed, although parents reported higher levels of negative effects. This result suggested that parents' considerations clearly have an influence on the way children perceive medication [69]. In the study of Gortz-Dorten et al, patients reported slightly but significantly higher satisfaction than parents. Overall satisfaction with the medication was high for 79.0% of patients and 66.1% of children also reported high satisfaction with how the medication helped them feel good. In conclusion, it is important to assess parental and child perspectives separately, with comparable questions, as their perceptions of medication are correlated, but only to a moderate degree [18].

Limitation 3: This was an observational study; assuch, selection of participants was based on loose criteria and treatment conditions are less controlled and standardized. This study design could be considered an advantage, from a different point of view, as it reflects routine care conditions in a pragmatic setting. This could be especially true for studies evaluating satisfac-

tion with medication, in which ratings from clinical trials are less informative as they are influenced by the fact that the sample is likely to be biased, given that those who agree to participate in the studies tend to do so because they are not satisfied with their previous medication [18-19].

Limitation 4: Both of our samples are comprised of parents who have already contacted specialized help. They have accepted the diagnosis and they decided to be involved in a therapeutic procedure, with some of them not treatment naive; parents who have not yet sought health care for their child may have different impressions and experiences. This may be considered as an important bias affecting perceptions, acceptance of the medication used and satisfaction with it.

6. Conclusion

Despite medical advances, barriers for families with children with ADHD in accessing medical services still exist. In this study, parents' perceptions, teachers' low educational status for the disorder and low recognition rate from the pediatricians were important factors of low accessibility of the medical services for diagnosis and treatment of the disorder. Most of the families having a diagnosis of ADHD and a prescription of a stimulant medication, followed medical advices. Stimulants, both short and long acting, were beneficial in improving ADHD symptoms. Parents were satisfied with the use of long acting stimulants, with older age of their child with ADHD being the only significant prognostic factor of their satisfaction level.

Author details

Antigone Papavasiliou¹, Irene Nikaina¹, Anna Spyridonidou² and Eleanna Nianiou³

1 Neurology Department, Pendeli Childrens' Hospital, Athens, Greece

2 Child and Adolescent Psychiatry Department, Sismanogleio General Athens Hospital, Athens, Greece

3 Department of Neurology, Iaso General Hospital, Athens, Cyprus

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