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SUMMARY

This research is based on the finding that though parents are in the forefront of child upbringing and are often the first to notice behavioral and educational differences, their role in the diagnostic process of ADHD diagnosis and treatment is unclear and not given attention.

This research will focus on the parents who have children diagnosed with ADHD. The central research objective is to find out what role parents play in the diagnosis of ADHD, and how they experience and cope with this condition in the Dutch society. The research explores the process whereby parents came to notice that something was wrong with the behavior of their child, how they sought for help and how the diagnosis of ADHD plays a role in how parents cope with their social environment.

This qualitative study is explorative and descriptive in nature and based on interviews with eleven informants among whom five health professionals and seven parents having children diagnosed with ADHD.

This study confirms that the cooperation between parents and teachers is at the core of the diagnosis of ADHD in children. Parents emphasized the role of teachers since they are involved in training which helps to bring out this type of behavior and they might be able to diagnose problems earlier than parents. Teachers therefore are valuable resource persons for parents. They can also provide valuable information on help seeking strategies. For example, most teachers are aware about the existence of Balans, the non-governmental organization in The Netherlands that provides information and advice to parents having children with behavioral problems.

For parents the most important issue in the etiology of ADHD seems to be its familial or genetic character.

Through my research I have been able to gain some insight in the help seeking processes of parents having children with ADHD. Family doctors are the first professionals that parents see, especially for children born without any complication.
Parents felt happy after their children were diagnosed as having ADHD, because the disorder is labeled, defined and is recognized medically. The diagnosis of ADHD in their children helped parents to explain the condition and its consequences to their environment and the community in general so that they might be able to deal with the behavior of their children more wisely.

This study shows that the presence of an ADHD child in a family can make life very difficult. Parents described the stress they and the siblings feel. This study confirmed general knowledge that parents and siblings of ADHD children are more likely to experience psychological distress than are those of normal children.

All parents having ADHD children were worried about the future of their children to have this disorder far into their adolescence.
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Chapter 1
INTRODUCTION

1.1. Background information.

A topic that caught my attention during my first stay in The Netherlands during the year 2000 was Attention Deficit Hyperactivity Disorder (ADHD), because the disorder is more common in the developed world than in the developing world, especially Africa. ADHD is known to occur in various cultures in North America, Europe and India, with variations in reported prevalence among Western countries.
ADHD refers to a developmental disorder of childhood characterized by a persistent pattern of inattention and/or hyperactivity-impulsivity that is more frequent and severe than is typically observed in individuals at a comparable level of development (American Psychiatric Association: 1994).
Since ADHD is until now mainly found in western countries, it is presumed that socio-cultural factors, i.e. the way parents perceive ADHD and their help-seeking behavior concerning the well being of their child, might play an important role in the prevalence of ADHD.

1.2 Statement of the problem.

Over the past ten years, ADHD has emerged from the relative obscurity of cognitive psychologist’s laboratories to become the “disease du jour “ of American school children and children in other developed countries such as The Netherlands.

For parents, getting information about ADHD depends on which professionals they see and what they read or gather from television and internet. Teachers are in the best position to detect abnormalities among children, especially minor ones, as teachers can observe children extensively, compare them to their classmates and thereby distinguish the normal child from the abnormal.
Since the treatment of ADHD is multimodal and the family plays an important role in psychosocial interventions (Silver: 1992), I would like to find out when parents start suspecting this disorder and how, when and where they look for help. Further I would like to investigate how parents cope with the diagnosis of ADHD in their children.

1.3 Literature review.

**ADHD: The Biomedical view.**

ADHD remains the most common behavioral problem in children in the developed world and represents significant challenges to children, families, schools and pediatricians with respect to children's ability to function, particularly in school. The biomedical diagnosis requires that some of the inattentive or hyperactive-impulsive symptoms are present before the age of 7, and some impairment from these symptoms must be evident in at least two settings, such as home, school or work. Clear evidence of impairment of developmentally appropriate social, academic or occupational functioning must be present.

It is very difficult to establish a diagnosis of ADHD in children younger than 4 or 5 years, because their characteristic behavior is much more variable than that of older children and may include features that are similar to symptoms of ADHD (Silver: 1992).

**Prevalence and gender difference.**

The true prevalence of ADHD cannot be accurately determined. However, the consensus of expert opinion seems to be that approximately 3-5% of the childhood population has ADHD. In The Netherlands, that equates to forty thousand children amongst whom boys outnumber girls by four to one. In roughly one third of these cases, the symptoms persist into adulthood (Health Council of the Netherlands: 2000). The number of children allegedly suffering from the disorder greatly depends on how one chooses to define and measure ADHD, the population studied, the geographic location of the survey, and even the degree of agreement required between parents, teachers and professionals.

Early estimates about the prevalence of ADHD varied between 1% and 20%. The diagnostic criteria for this neuropsychological disorder should and do consist of more than simply
establishing a level of statistical deviance on a rating scale. The diagnostic Statistical Model-III (DSM-III) also requires an early onset of symptoms (before age 7), pervasiveness across settings, the exclusion of several other disorders, and most important the impairment in one or more major domains of life functioning (American Psychiatric Association: 1994).

**Etiology of ADHD.**

The causes of ADHD are not fully known. The literature suggests that both biological and genetic factors are involved (Compernolle: 1996). It is suggested that children with ADHD suffer from an underactivity of the brain’s behavioral inhibition system (Quay: 1989) or from impairment in delayed responding, similar to patients with frontal-orbital lesions (Barkley: 1994).

Goodman & Stevenson (1989) found that the concordance of ADHD is higher in monozygotic than in dizygotic twins. This supports the notion that genetic factors are significant causally. Also ADHD has been found to be more common in the first-degree biological relatives of children with ADHD than in the general population (American psychiatric association: 2000). This is consistent with the genetic hypothesis of the causes of ADHD.

For many years, evidence has existed showing higher rates of psychopathology, particularly depression, alcoholism, conduct problems and hyperactivity among the biological parents of ADHD children (Silver: 1992).

Maternal consumption of alcohol and cigarette smoking during pregnancy has both shown relationships with the degree of ADHD symptoms in the offspring of these mothers. Environmental causes may also be involved. For example it has been reported that an insufficiently structured environment can enhance ADHD symptoms. However, a lot is to be done concerning the etiology of ADHD (Barkley: 1994).

**Inattention.**

Inattention is revealed in poor selective attention (attending to irrelevant or distracting stimuli and ignoring relevant stimuli), and lack of sustained attention (the ability to keep paying attention overtime) (Douglas: 1972). Children with ADHD are easily distracted and avoid tasks that require paying attention for a long time span. These difficulties are sometimes
apparent in free play settings as evidenced by shorter duration of play with each toy and frequent shifts in play across various toys (Barkley et al., 1990).

**Impulsiveness or behavioral disinhibition.**

ADHD is frequently associated with a deficiency in inhibiting behavior in response to situational demands or what may be called impulsivity, again relative to others of the same age and gender. Impulsivity is expressed in lack of control in situations that require controlled attention or a structural approach. Children with ADHD are inclined to respond to the first thought in their mind, they do not consider sufficiently the effect of their behavior and find it difficult to delay the fulfillment of their needs (Van der Krol et al., 1998).

**Hyperactivity.**

The third characteristic of those with ADHD is the excessively or developmentally inappropriate level of activity whether motorically or vocally. Restlessness, fidgeting and generally unnecessary gross bodily movements are common (Barkley, Cunningham, 1979). These movements are often irrelevant to the task or situation and at times seem purposeless. Parents often describe these children as “always up and on the go”; acts as if driven by a “motor” or “can’t sit still”. Observations of those children at school or while working on independent tasks find them out of their seats, moving about the class without permission, restlessly moving their arms and legs while working, playing with objects not related to task, talking out of turn to others and making unusual vocal noises (Barkley et al., 1990).

Nevertheless, inattention, impulsiveness or behavioral disinhibition and hyperactivity are not necessarily displayed at the same time or the same degree in ADHD. The most often cited characteristics of children with ADHD are in order of frequency; hyperactivity, perceptual motor impairment, emotional liability, general coordination deficit, attention deficit (short attention span, distractibility, perseveration, failure to finish tasks, inattention, poor concentration), impulsivity (action before thought, abrupt shifts in activity, lack of organization, jumping in the class), memory and thinking deficits, specific learning disabilities, speech and hearing deficits, equivocal neurological signs and electroencephalogram irregularities (Goldstein: 1992).
ADHD has a wide impact on the development of children in learning, speech and language and it is associated with a magnitude of problems such as sleeping, emotional, relational, behavior problems and problems in sensory and motor activities. Sometimes these associated problems are so prominent that they obscure the existence of ADHD (Silver: 1992).

In the current version of the Diagnostic Statistical Manual classification system, (DSM IV, APA, 1995) ADHD together with oppositional defiant disorder and conduct disorder comprise the cluster attention deficit and disruptive behavior disorders. The co-morbidity of these three disorders is high (Hinshaw: 1994) and it is often difficult to decide diagnostically between them.

**Subtypes of ADHD.**

According to DSM-IV, there are three subtypes of ADHD.

The first subtype is labeled as attention-deficit/hyperactivity disorder, combined type. This label should be used if six or more symptoms of inattention and six or more symptoms of hyperactivity-impulsivity have persisted during the last six months.

The second subtype is labeled as attention-deficit/hyperactivity disorder, predominantly inattention type. This label should be applied if six or more symptoms of inattention, but fewer than six symptoms of hyperactivity-impulsivity have persisted for the previous six-month period.

The third subtype is labeled as attention-deficit/hyperactivity disorder, predominantly hyperactive-impulsive type. This label is applied if six or more symptoms of hyperactivity-impulsivity, but fewer than six symptoms of inattention, have persisted for the previous six-month period.

However, individuals may be diagnosed as having one subtype of the disorder at one period of time and may develop another predominant subtype at a later date. But if the specific criteria are no longer met for the existing three subtypes, the diagnosis made is attention-deficit/hyperactivity disorder, in partial remission.

**Treatment of ADHD.**

ADHD is a complex syndrome associated with a large number of symptoms, and numerous other diagnoses and deficits seen to coexist with it. A variety of treatments have been
attempted with ADHD children over the past years (Ross & Ross: 1982). Vestibular
stimulation, biofeedback and relaxation training among others, have been described as
potentially effective in uncontrolled case reports, yet are lacking in well-controlled
experimental replications.

Many dietary treatments, such as removal of additives, colorings or sugars from diet or
addition of high doses of vitamins have proven very popular despite minimal scientific
support. Treatments with some proven efficacy have been pharmacological. The most
commonly prescribed drugs are Methylphenidate (Ritalin), d-amphetamine (Dexedrine), and
pemoline (Cylert). Often these drugs are considered together with psychosocial therapy,
cognitive-behavioral training of ADHD children and parent training in contingency
management techniques.

None of these available present treatments is curative of ADHD symptoms. Their values lie in
temporary reduction of symptom levels or in the reduction of related behavioral and
emotional difficulties, such as defiance and conduct problems, depression and low self-esteem
or academic underachievement. When such treatments are removed, the level of ADHD
symptoms appears to return to higher or pre-treatment ranges of deviance. Their effectiveness
in improving prognosis thus rests on their being maintained over long period of time (often
years) (Silver: 1992).

ADHD: its sociocultural birth in the developed world.

Literature reading shows that symptoms now labeled ADHD were not discerned as medical
problems in Europe and other developed countries in the late nineteenth and early twentieth
centuries. Symptoms now labeled ADHD were seen as characteristics of unruly and disruptive
child behavior. The label came out as a result of medicalization of this particular child
behavior.

Certain socio-cultural developments are thought to play a role in the birth of the phenomenon.
The extensive and rapid transformation brought about by urbanization, industrialization,
introduction of compulsory schooling and the corresponding changes in living conditions,
social relations, and mentalities brought about new problems and contradictions. Deviant or
abnormal children became the objects of increased public, educational and medical concern.
The role of teachers.

The transformation of social relations that accompanied urbanization and the industrialization process (i.e. the increased interdependence among different social strata, the concentration of new underclasses in the major cities) raised everywhere in the developed countries a growing political concern with public order. In this context, the issue of popular education assumed a new profile. School began to be seen as an institution that could moralize the masses, provide a substitute for a home environment presumed to be deficient, instill a sense of belonging to a national community while, at the same time, providing children with the frame of mind appropriate to their social condition (Maynes: 1985). In other words mass education was primarily intended as a means for propagating civic virtues, and instilling appropriate work habits among the population that, in the project of the reformers, would enable the eventual eradication of both poverty and anti-social practices.

Accordingly, great importance was attached to the selection and training of teachers, to the pedagogical approach and to the notion of a correct space for schooling. The classroom became a specialized space in which the fine details for the classroom’s physical organization were to epitomize the pedagogical program the school was meant to implement. Reform of the teaching profession took place and teachers became targets of public inspection and control. Also government was shaping the professional profile of teaching, and teachers took initiatives in order to raise their social and economic status with the emergence of associations in various countries (David: 1980).

The improvement in teachers’ social and economic status was seen as a way of promoting their specialist knowledge and competence, a resource that, in turn, would have allowed teachers to reach an autonomous position and to play a role in shaping educational policy (David: 1980).

Discipline was introduced in school and with reform in the pedagogical system, the individual method of teaching in which every child was taught in turn by the teacher, and which had been predominant in previous forms of popular education, was abandoned in favor of the simultaneous method, in which children were all taught at the same time (Thompson: 1974). The latter method operated under the assumption that virtually all pupils would be able and willing to understand (and comply with), teacher’s instructions at the same pace, and that they
would sit quietly and still at their designated place, focusing their undivided attention on their teachers during the lesson.

With this, emerged all kinds of individual deficiencies and inabilities. Hearing, sight, and speech defects that would previously pass unnoticed, or would simply be considered a child’s or family’s misfortune, became obstacles requiring medical evaluation and management through remedial action with creation of special schools. In addition to children suffering from sensory handicaps, however, other problems arose with pupils who, though apparently normal, seemed unable or unwilling to follow their school lessons and to comply with disciplinary rules. Pupil’s lack of discipline, in particular, generated serious classroom management problems for teachers. Lack of discipline represented a problem that transcended the classroom level and teacher-pupil relations.

School had been established as an outpost of civilization, a place whose moralizing influence was supposed to radiate into families and into the community at large. Disruptive pupils needed to be managed in a way that reflected consideration for the school’s intrinsic objectives. Since the school was instructed with a civilizing mission it had to reach everybody, to instruct and moralize the greatest possible number.

To increase the number of pupils regularly attending school was thus a primary concern. Children who might eventually benefit from such pedagogical intervention were therefore to be distinguished from children who were unfit, unteachable, and unredeemable and required an alternative form of education or re-education.

The influence of medical perspectives.

Child unruly and disruptive behavior became a great concern and solutions were sought. Governments and educational authorities consulted medical doctors and psychiatrists since they had already made their inroads into the educational system through their campaigns for the sanitation of the school environment (ventilation, lighting and cleanliness of school rooms) in the context of the hygienist movement that in the course of the nineteenth century had promoted public measures for urban sanitation. They had also discussed the potentially deleterious effects of school education upon the physical and the mental health of children. By the end of the nineteenth century child unruly and disruptive behavior became the focus of medical concern. To a great extend, this increased medical attention for children was related
to the introduction of compulsory popular education. School, on the one hand, provided the conditions that allowed for the generalization of clinical observations to encompass large number of individuals. On the other hand through the imposition of an exclusive pattern of conduct and learning, it brought into focus all kinds of child difficulties, deficiencies, and behaviors that clashed with the standards required by school.

Doctors began to find elements to describe children or diagnose with unruly and disruptive behavior. Elements such as lack of attention among pupils, unresponsiveness to punishment, restlessness, fidgeting, excessive talking, and inability to sit still became an essential part of the clinical picture of child instability and moral deficiency or attenuated symptoms of similar organic pathology (Dupre: 1913). This established the theoretical basis for the medical assumption that unruly behavior among children is grounded in neurophysiological pathology.

Other groups of people such as psychologists and educationists all became involved. Therefore child unruliness took another dimension and became to be regarded as a disorder, of which the etiology and clinical features had to be enlightened.

Nevertheless there were a lot of conflicts among the professional groups involved. Identifying school children with these problems proved difficult and an uncertain enterprise for doctors. The initial identification was based on educational criteria related to pedagogical exigencies, and concerned types of behavior that caused major disciplinary problems within the classroom with no regard for the signs and stigmata proposed by the medical approach. The many complaints by psychiatrists pertaining to teacher’s inability to identify true abnormal children demonstrated that medical categories did not have much influence on teachers’ conceptualization of what constituted a ‘defective child’ (Rose: 1985). Teachers however, at least initially remained quite insensitive to the medical appeal. Apart from the obvious difficulties that they encountered in grasping some principles on which the medical approach was based, the problem was that teachers’ and doctors’ understanding of child difficulties were fundamentally different. The gap between the diagnostic methods of doctors and teachers perception of pedagogical and management problems proved difficult to bridge.

As writing above, pupil unruliness was problematic for teachers, but this did not automatically imply that teachers assigned a pathological meaning to it. Teacher’s cooperation in the diagnostic process was essential to legitimize the medicalization of problems and troubles emerging in the school context. Doctors argued that teachers were in the best position to detect abnormalities among children, especially minor ones, as teachers could observe
children extensively, compare them to their classmates and thereby distinguish the normal child from the abnormal. In this context, doctors stated that teacher’s reports and information on child behavior were an essential complement to medical diagnosis.

Nevertheless doctors continued their search for the medical evidence for the cause of child instability. Some suggested it might be found in lethargic encephalitis that was followed by enduring after-effects (attributed to the brain inflammation caused by the disease), such as overactivity, restlessness and impulsivity, which in some respects were similar to those observed in unstable and morally deficient children. But several studies discarded that point of view.

In general doctors agreed that some kind of still undetected congenital or acquired illness could be the cause of child unruliness. But the most important part in the propagation of child unruliness and disruptive behavior as a specific syndrome was due to the important transformations that relate to changes in the balance of power between social classes, and increasing state involvement in education health policies.

Meeting point of teachers and doctors.

Welfare policies, economic growth, and full employment improved the general health condition of the population. The number of undernourished children decreased sharply, while new minor child psychological disorders appeared in psychiatric classifications. New definitions appeared to designate child emotional conditions and behavior that did not disrupt classroom routines but the child’s performance and self-esteem. The two most common ones were the hyperemotional child, hypersensitive and excessively prone to depression, and the timid child, haunted by feelings of guilt and self-devaluation that interfered with its school performances.

The fact that women became independent economically and their growing emancipation was interpreted as a threat to family stability and re-elaborated as another element of child destabilization. Bowlby (1951) argued that children who did not spend their early infancy with happy and content mothers would probably develop into pupils who lacked concentration at school, individuals who were emotionally and socially maladjusted, unable to care for others, and inclined to develop conduct disorders and delinquency. The absence of the father, on the other hand, was judged to be damaging only at a later stage of a child’s life.
Some studies argued that paternal absence might also be one of the causes for the rise in juvenile delinquency.

Schools were assigned more personnel, teachers received higher salaries and the schools were given additional equipment. A lot of psycho-pedagogical interventions aimed at improving school success rates were implemented. Such interventions also deal with problems of pupil maladjustment (which had increased with the growth of school population). These remedial measures implied increased contact between teachers and clinicians. Eventually, the medical approach joined the concerns of pedagogy. This combination of medical and educational criteria gave rise to a medical conceptualization that postulated a direct link between school behavior and performance, and mental and nervous disorders (Rose: 1985).

Psychiatrists and psychologists were given the task of assessing the nature of problem (poor school performance and or unruliness might depend on intellectual deficit, ‘sociocultural disadvantage’, or emotional problems). They could certify the child’s condition and entitle the school to request special educational provisions. In this way, psychiatric and psychological approaches to child rearing and education increasingly influenced teachers’ and parents’ conceptualizations of unruly and disruptive behavior among children and became the normal way of interpreting child unruliness. On the one hand, this encouraged teachers to conceptualize a wide range of unruly and disruptive behavior as possible symptoms of emotional problems to be assessed and treated by clinicians. On the other hand, the enlarged responsibility of teachers towards their pupil’s emotional condition and the increase in prohibitions against corporal punishment and disciplinary sanctions to re-establish classroom order, induced teachers to turn to a referral system in order to deal with their unmanageable pupils (Walkerdine: 1986). This led to a rise in the number of referrals and the increase in the demand of special educational provisions.

Role of parents.

Parents tended to comply with school requests and, to some extend, also supported the extension of the psychiatric-psychological services. They gained from having the school behavioral problems of their children re-defined as medical or psychological problems that needed to be dealt with by remedial and not disciplinary intervention (Swaan: 1988). Parents
also gained in cooperating with school requests and others because they had hope that the behavioral problem of their child, if recognized medically, could be solved with the use of drugs. Furthermore, the fact that they felt guilty about their child behavior would no longer exist. Silver (1992) described that parents may be at risk of experiencing excessive stress for two reasons. First, it is a challenge to raise a child with ADHD. Second, because there is hereditary predisposition to this disorder, these parents themselves have a higher rate of ADHD and psychiatric problems than general population. Studies show that up to twenty percent of mothers and up to thirty percent of fathers of children with ADHD also have ADHD. Furthermore, there is a greater chance of ADHD among the biological siblings of ADHD children; thirty to thirty five percent may have ADHD.

Parents do not only play a role in child raising but are highly affected when their children have a behavioral problem. Parents of children with ADHD are more likely to experience a variety of psychiatric disorders than parents of normal children. Professionals therefore felt that some parents need help dealing with their reactions to the diagnosis such as denial, anger, frustration, sorrow, depression, blame and guilt. Therefore, several ways have been used to include parents in the management and understanding of children with ADHD. Dornbush and Pruitt (2000) showed that it is essential that parents become familiar with and understand the clinical manifestations of ADHD and other developmental disorders. Literature shows that the family plays an important role in helping children with ADHD. Through family therapy, parents and other family members may learn how to create a more positive family environment and to more effectively relate to the child. For example the family therapist may identify family situations in which the child reacts aggressively and help the parents and siblings modify the way they respond when the behavior occurs (Dornbush and Pruitt: 2000). Moreover, the increased attention devoted to children’s emotional condition also resulted in an increased dependence of parents on experts.

Pharmaceutical companies might also have played a role in the incidence of ADHD. They developed drugs to treat children with ADHD. The drugs received a lot of publicity and were presented as the solution for academic problems of children.
1.4 Research objectives.

I sketched how the concerns of medical and educational professionals converged in the creation of a label that is basically medical, but that is applied on the basis of behavioral and educational problems and that is treated with a combination of medical and behavioral interventions. Though parents are in the forefront of child up-bringing and are often the first to notice behavioral and educational differences, their role in the diagnostic process of ADHD diagnosis and treatment is not given attention and unclear.

This research will focus on parents who have children diagnosed with ADHD. The central research objective is to find out what role parents play in the diagnosis of ADHD, and how they experience and cope with this condition in Dutch society. This general objective can be divided into three specific objectives:

1- To explore the process whereby parents came to notice that something was wrong with the behavior of their child.
2- To gain insight into the help seeking process of parents concerning their children’s behavior.
3- To explore the role of the diagnosis of ADHD in how parents cope with their social environment.

The following research questions will be looked into.
When and through which experiences did the parents start suspecting different behavior in their child?
What is normal child behavior from the parents’ perspective?
What is the help seeking behavior of parents having a child that is behaving differently?
How do parent parents perceive the diagnosis of ADHD?
How do parents cope with their child in the social environment?

In chapter 2, I will present the research methodology. Chapter 3 will be the presentation and analysis of data, and in chapter 4 my findings will be discussed. I will conclude my thesis in chapter 5 with a short reflection on the implications of my findings.
Chapter 2

RESEARCH METHODOLOGY

2.1 Introduction.

This study is exploratory and descriptive in its orientation. What are the experiences and perspectives of parents having children being diagnosed with ADHD in the Netherlands?

The study took place during a period of six weeks from 16th May 2002 till 27th June 2002. It was difficult to contact parents due to the fact that many parents were on vacation and also most parents contacted were not willing to talk about what they consider to be very private and sensitive. Therefore I did not use names, and where necessary just a letter of the alphabet was used for confidentiality. For the same reason the names of towns where interviews were performed are not mentioned. In addition, by introducing myself, explaining to the informants the objectives of the research, I informed them about the purpose and the procedure of the research. At each interview session, I asked informant if I can take notes and if the interview could be taped for later transcription. I also promised a copy of my thesis to most of my informants. Data from the study were processed manually. Analysis of the data was based on the general and specific objectives and research questions, describing the experiences and perspectives of parents having children being diagnosed as having ADHD in their own way of talking.

2.2 Selection and Study Area.

The fieldwork is performed in The Netherlands, a country of about forty thousand square kilometers and with a population estimated at sixteen millions. The fieldwork was not carried out in a specific region. The researcher traveled wherever the informant was living/located. The informants were gotten by snowballing and with the aid of my supervisor and classmates. Since I do not speak Dutch my key informants helped me to contact parents that were interested in talking about their experiences and perspectives. A total of twelve informants participated in this research. Seven were parents of children having ADHD. Six of these parents were mothers of a child diagnosed with ADHD and one was a father (because the
mother had difficulty speaking English). Most fathers did not want to talk about their experiences and perspectives. They told their wives that they were busy with work and did not have time. I even suggested to come in the weekend but was told that weekend was the only time they had for household activities.

Also five health professionals amongst them, a member of a non-governmental organization, a psychiatrist, two pediatricians, and a child psychologist took part in this research. They provided me with insight into the medical perspectives on approach to ADHD.

2.3 Data Collection Techniques.

In-depth interviews with parents of children with ADHD were held in several locations and almost all the parents were enthusiastic and wanted to know more about my final findings and the reasons of my interest in a disorder of which they thought that it only exists in the developed world. The informants spoke English and the communication was good.

In-depth interviews with parents were done with a high degree of flexibility. The questions were open. This gave the interviewee the opportunity to answer from his/her own experiences, feelings and thoughts. A topic list was used for interviewing informants: normal child behavior, help seeking, community attitudes toward parents, and social effect of ADHD diagnosis.

In-depth interviews with key informants (health professionals and also a representative of a non-governmental organization dealing with children with ADHD); a more structured interview guideline was used since the time available for these professionals was limited. The interview guideline can be found in the annex section.
Chapter 3
PRESENTATION AND ANALYSIS OF DATA

3.1 Health Care Concerning ADHD and Others Mental Disorders.

According to the health professionals in this study, childcare provisions pertaining to behavioral problems depend on the age of the child. Children less than two years will be attending ‘the consultatie bureaus’ which are primary health care clinics where normally all Dutch children within that age range go. In these health centers, women bring their children for routine care, such as immunization visits, screening for deafness, or problems with sight. Doctors trained in screening children and nurse who are skilled in recognizing developmental problems run “Consultatie bureaus”. Those professionals are not allowed to refer children themselves. They report their findings to the general physicians who then refer children appropriately. Children in the age range between two and eight years are referred to the pediatrician and children older than eight years are referred to the ‘Regionale Instelling voor Ambulante Geestelijke Gezondheidszorg’ (RIAGG). In either place of referral, the pediatrician together with the child psychiatrist will make the diagnosis of ADHD and they will offer treatment and give guidelines to parents through the educational officer working at their services, or they might refer them to a ‘Medisch Kinder Dagverblijf’ (MKD), which are day care centers for children with developmental problems. In those day care centers children are oriented academically in small groups, and parents are offered psycho-education in the case the child is less than eight years old. If the child is older than eight years and has mental problems he might be seen by a child psychiatrist but if the child rather has psychosocial problems he will be sent to the RIAGG where multidisciplinary teams offer support to parents and training to children and if necessary medications. At the RIAGG teams consist of, among others, are a child psychiatrist, a psychologist, a special educationist, specialized nurses and social workers.
3.2 Normal and Abnormal behavior.

From my interviews, it appears that the process of diagnosing ADHD in a child usually starts with (one of the) parents sensing that their child is in someway different from other children. Parents begin to worry about their child when he or she starts manifesting behavior, which they consider to be different from normal child behavior. Parents described normal behavior in various ways.

Three parents were of the view that it is normal for a child to behave spontaneously and that when corrected by parents, teachers or others, he will understand what you mean and act like you want him to, even though this might not happen immediately. They were of the opinion that most normal children react positively when you say ‘don’t do that’, and that they are prepared to listen and do what parents, teachers and others tell them.

Two other informants emphasized the ability to learn. They defined a normal child as one who learns from past experiences. This presupposes the ability to remember what has happened in the past. Listen to this mother talking about normal behavior:

*When you ask something from a child and he refuses to do it, after persisting in asking or asking in another way he still refuses to do it then you think there is a problem. The behavior is a reaction to the things the child hears, smell etc...a lot of senses are involved in recognizing and exploiting the situation. A normal child knows that doing something good leads to rewards and keeps remembering and doing good things. He or she knows and keeps remembering that doing wrong things results in punishment, so he or she learns not to do the wrong things. With that the child learns new behavior.*

For other informants, a child behaves normally when he or she is able to undertake new adventures, is not very scared, and able to integrate himself or herself socially by playing with other children, and can be taught what is right and wrong. One mother was very explicit in describing how the confrontations of her child with others made her suspect that something was wrong.

*As a mother, I found that things were not going on well with the child and his surroundings. With me yes. But when people were around things did not go on well and new things around made him very excited.*
Some parents came to the insight that something was wrong by comparing their child with other children or siblings:

*She is not normal compared to her junior brother who is three years younger than her. I just have to be careful about what she does. She needs a lot of attention compared to her brother.*

Another mother said:
*I noticed that he did not behave as my first child, very calm, very active, already had strong emotion.*

Most of my informants noticed that their child did not conform to their expectations of normalcy at a very early age, for some even when the child was only a baby. Even though some parents could not remember the whole developmental history of their child, all could recall that they noticed that something was different in the development of the child. Some remembered specific signs. For instance, a mother said:
*He was born very small (thin), did not cry at night for milk. By the first week of life he had lost five hundred grams. He could not be aroused and developed into a baby who was never satisfied unless you paid attention to him, or played with him. He did not crawl, walked only at the age of eighteen months and then I realized that he was different.*

Another mother narrated:
*As a baby I saw it already. He was very angry. He woke up five times at night, very restless, not a happy baby, never had a complete night till he was four years.*

Another said:
*He was twenty-one months old when our second child was born; he was very small, did not react to the word “don’t” or “no”, had a fighting character even at that young age.*

And another:
*My son was about five years and was very strange. Did not like things that children of his age do like and always staying by himself. Not playing. I just knew something was wrong and I went on to ring the bell immediately.*
Some parents became fully aware of their child's abnormal behavior only after the child started schooling. Informants told me that teachers play an important role in noticing that their child behaves different.

A mother said this about her daughter:

*When she started school, the teacher did not go along with her, she became very isolated, always angry and very oppositional, and then I began to seek for help. She was five years old.*

Another mother said this:

*When he was six years old, he started school in a small group and after two weeks, complaints came from the teachers and I had to ring the bell by seeing a pediatrician, then a child psychiatrist who put him on Ritalin.*

All parents expressed faith in the insights of teachers and said that they had taken the advice of the teachers very seriously. Teachers not only confirmed their feelings that something was not right in the behavior of their children, but also stimulated them to seek help for their child.

*I thought he is sweet, he is a dreamer, he is slow, but he is also bright. Last year he had to go to secondary school. He had the same teacher as his sister. The teacher called after sometime to tell me that “S” has some problems in organization. I tried to help him with lessons but he said he wanted to do it himself. So after three months, I got a phone call from school saying that “S” has very low grades. I looked into his agenda, he didn’t write down his homework, I looked at his papers he didn’t take notes. So I decided to let him have a test with a psychologist who let him have several developmental tests, then ADHD was diagnosed.*

In the process of diagnosing ADHD the media play a role as well. Many parents reported that media such as newspapers have helped them to become aware of ADHD by giving clues about the way an ADHD child behaves.

For example;

*After noticing as a mother that things were not going on well with my son, I read in one of the magazine about ADHD. There was a checklist of fourteen items, which I used and diagnosed that my son was having ADHD since he scored thirteen items out of fourteen.*
Health professionals also emphasized this issue in my interviews with them. According to them the role of the media in the growing popularity of the diagnosis of ADHD is important but not unproblematic. Media can influence parents in such a way that they notice behavioral abnormalities in their children, which are not necessarily there:

*When parents come to the hospital, they said, after reading from magazines, Internet, television: my child has ADHD.*

Health professional confided that sometimes the idea that the child has ADHD is so difficult to reverse that it makes encounters with parents at the hospital very difficult, since they need more time to explain what is at stake with the child and parents get very nervous and anxious during investigations to determine the diagnosis.

A mother said this:

*When we took him to the hospital, we just wanted the child psychiatrist to give him Ritalin and tell us how we have to behave with him since we already knew that he had ADHD after reading about the clinical features of ADHD in the magazines and Internet.*

Nevertheless, despite the fact that most health professionals thought that parents are very enlightened on this issue of ADHD when they come to them, only two parents had previous knowledge of ADHD.

### 3.3 Help Seeking.

Most parents looked for help as soon as they felt that their children were not behaving normally. It seems that in general they had few problems finding their way through the Dutch health care system.

*My son was about five years and was very strange. Did not like things that children of his age do like and always staying by himself. Not playing. I just knew something was wrong and I went on to ring the bell immediately. I went to the RIAGG and there the process went on very fast. I was sent to a pediatrician, then to a child psychiatrist. Drugs were given and for several months we had conversations.*
For most parents the first step in the health seeking process was to visit the family doctor, sometimes having been alerted to the disorder through reading magazines.

A mother said this:

After reading in the magazines about ADHD and trying to understand my son and thinking he may have ADHD, I went immediately to my family doctor and I told him I wanted to be referred to a pediatrician.

Parents did seek for help as early as possible, sometimes before the child started school. This happens when parents noticed at an early age that the child is behaving differently.

At two years my child was sent to a pediatrician then to a child psychiatrist and the conclusion was that of hyperactivity with lack of concentration since ADHD could not be diagnosed at that age.

But in school children academic underachievement was one specific factor that made most of the parents seek for help.

For example:

When she was in group three, her teacher said she has a problem with mathematics, we saw that it is short-term memory because she could not remember the things she had to do. So we knew we have waited until the symptoms came from school since it was not a problem for us but we did not want her to have problems with school.

This does not mean that parents never had second thoughts about help seeking. Some parents did not seek help because they felt that the diagnosis of ADHD would not change their child in an essential way, the child would remain who he is, having ADHD as a character trait.

Also parents were afraid about the side effects of the drugs used since they believed the drugs affect the brain and might have serious side effects in the future. For example a mother kept giving her son drugs only intermittently because she was afraid about the side effects of the drugs:
He got Ritalin once, for some few months because nobody knows about the side effects. It is a drug that affects the brain. He takes the Ritalin now only during exam periods let us say for about three weeks.

Other parents thought they could handle their children’s behavior within the family. Some parents did not seek help because they tried to find a reason for the child behavior. A mother said this:

*I did not take her to hospital at first because I thought there are reasons for her to behave the way she did since we move from Zaandam to here. My husband and I always knew deep inside that there was something more. But to be honest, I thought we could do it.*

### 3.4 How do parents’ perceive the diagnosis of ADHD?

The result of this fieldwork showed that most parents seek help because not knowing what causes the behavioral problems is very stressful for parents. They tend to blame themselves and feel insecure about their role as parents, but when ADHD is diagnosed they are given the certainty that they are not to blame, that they are not the cause of what has happened to the child.

The parents I spoke to, in a broad sense were well aware of the medical definitions of ADHD. They described ADHD as due to a disconnection in the brain. Most parents acknowledged that ADHD is genetic, that it is due to something in the genes. Sometimes they would say that ADHD is familial.

A mother said this

*I think it is genetic, let us say familial. Everyone I talk to has someone in their family with some of these problems; also in my family.*
Another woman said:

*I think ADHD is caused by genetic factors since two of my children have ADHD, also a brother of mine has it and there are a lot of children in my husband’s family who went to special schools. My brother has a nervous kind of behavior and I see that in my children.*

A mother emphasized this by saying:

*You see ADHD is genetic. I have also been diagnosed as having ADHD also I have a lot of wild people in my family like my uncle, grandfather and many of my cousins. I have this believe that ADHD is due to something in the genes.*

By being able to attribute the disorder to a familial medical problem, feelings of guilt and shame disappear. A mother described with emotion what she felt after the diagnosis of her daughter as having ADHD.

*At first I was, how should I put it, I felt like she got a sort of certificate. I was glad because all the years, it had taken three years before we got the final diagnosis. All those years I got messages from the outside; always we were to blame. So when I got the final diagnosis I felt relieved because I wasn’t to blame.*

By receiving a medical diagnosis hope is created that something can be done to improve the situation of the child. Parents spoke to me about their relief after the diagnosis. They had strong feelings that since the problem was recognized and labeled it could be coped with and that they would be going to get support from the health professionals to solve the problems.

A mother puts it this way:

*We were very satisfied at the diagnosis. For us it was just a kind of relief since what we thought was that the abnormal behavior has a name, it can be treated. This is not our fault and we cannot do something about that.*

One parent made it explicit that the diagnosis of ADHD was important for her since she could now tell her surrounding that her son was having ADHD so that they might understand why he was behaving the way he did.

She said:
For my own, I do not have any problem with him. But the problem is existing when he is out of this house. In this house, the problem begins when there is another person around. I was surprised when they said he has ADHD, but he did not bother me. But it is easy when they said he has ADHD then you say it to the teacher so that they will treat him otherwise and also to the family so that they will know that he cannot do anything about his behavior.

Among my informants one parent believed that ADHD was due to familial and genetic factors but also believed that some parents might have a satisfaction saying their children has ADHD. A mother narrated this:

*I think ADHD is genetic or familial even though my son is the only person in our families with ADHD. Nevertheless a lot of parents are happy saying that their child is ADHD just to have the benefit of it. Also when parents cannot handle their children they just said he or she has ADHD just to make it easy on themselves. Such parents are too easy with medicines, do not make any effort to handle the child because they are very busy with their life, and work, they choose what goes easy like saying to people that the child has ADHD.*

3.5 Parents’ coping strategy.

Of course the process of seeking a diagnosis and treatment of the behavioral problems and other symptoms of their child by consulting with professionals, in itself may be described as a coping mechanism. In this paragraph, however, I will concentrate on the coping strategy with the behavior and with the problems caused by this behavior.

Parents found several ways of coping with the behavior of their child. The most important was ‘talking to friends’, especially about how to raise a child. The majority of the parents said sharing their problems with friends relieved them, and some parents by doing that even made new friends among those also having children with behavioral problems, not necessarily ADHD.

*Talking with friends was enough. Also when I went to Balans, I saw that many parents were having the same type of problems. So I started working like a volunteer.*
Some parents learned strategies to cope with ADHD by reading in magazines and talking with professionals.

A mother said this:
*I was told life has to be structured so I developed a system where we have to eat at the same time and place. Also I had to warn myself to check on him if I had asked him to perform a task.*

Other parents try living from day to day, correcting abnormal behavior by creatively using techniques described in web sites, such as find out what are your child interests, limit television and video games, find your child’s best time of alertness, provide positive role models, spend positive times together among others.

The presence of an ADHD child in a family influences the other family members. Parents complained that the ADHD child always is at the center.

*When my daughter is at home everybody has to turn towards her. She knows everything, intruding in all, has a way of drawing the attention towards her. This has made my son not to like her at this moment because. He now draws the attention to him.*

Other siblings are in competition with them since all children love to have equal attention.

*My ADHD son is always in conflict with my non-ADHD daughter because both of them are competing for my attention. Deep inside they love themselves very much but my daughter also wants the same attention as my son.*

Siblings therefore also apply coping mechanisms; the most important one is gaining information about the disorder, e.g. giving a presentation in school. Some children became so much affected with the behavior of their ADHD siblings that they decided to study in that direction, on everything that has to do with ADHD.

A mother emphasized that:
*My eldest daughter became affected with the behavior of her sister. She learned about psychological behavior, everything that has to do with ADHD. Last year she even started*
reading medicine at The University of Amsterdam and had to stop this year because she didn't like the course anymore. Now she is studying Greek's literature.

In few cases the father was so much affected by the child behavior that he temporarily had to leave the house after advice from health professionals.

*My husband was advised to leave our house for sometimes by health professionals because he could not bear the behavior of our son. He is now fifteen years but behave like a child of thirteen years and my husband cannot understand. He is always blaming himself concerning our son, he feels guilty.*

But in most cases, the family members were very supportive of each other. However, parents also have to cope with the fact that ADHD is a chronic condition. All the parents were of the opinion that ADHD cannot be prevented nor cured.

A mother said:

*ADHD cannot be prevented or treated. But we can learn strategy to live in a very stable way with ADHD.*

Another mother emphasized that:

*When a child is diagnosed as having ADHD no matter what is done, he or she never becomes an average sort of person. Also since ADHD is familial or genetic it cannot be prevented.*

This implies that albeit medicines may be able to suppress the symptoms, the disorder will always be there, and the child will have to cope with it during his or her whole life. Parents are conscious of the fact that the success of their children to do this partly depends on the society they live in. Parents believed that the type of society they live in can influence the way of coping with ADHD, saying that in open and well ordered societies people having children being diagnosed with ADHD know what they have to do to find help and solutions. In confrontation with me, an African interviewer, they all said that they thought that in societies without well-ordered infrastructures the problems are bigger since ADHD would simply be regarded as an unruly behavior, as it was regarded earlier in Europe too.

But even in their own country parents worry a lot about the future of their children. They felt they could help their child now because they are only teenagers. The question on their mind
was would she or he take the right decision after puberty? As long as parents have the responsibility for their child, they felt things went on relatively well with the aid and advice from friends, books, media and the usage of medications. But for the future they can only hope that the child as an adult takes the right decision and continues with medication and seeks help from health professionals.

A mother narrated this:

*My daughter of eighteen years stopped with Ritalin at the age of fourteen saying to everybody that she was normal, accusing the whole family and us. Surprisingly one month ago she came to me saying: mama I think I do not behave as my friends do, I cannot stop intruding when people are talking. I think you people in this house are right. I do have ADHD. Please can you give me some books so that I can read about it and what I can do to control my behavior? I know the answer, I have to see the family doctor and go back on medications. And that is what she did. At the end she came and told us this: Thank you mama and papa for all what you did. Thanks for allowing me to grow up in this house with you and my siblings, thanks for not sending me to a reeducation home, and thanks for all. I love you.*

Some parents feared the worst that their children might go into bad living habits such as drug addition and aggressive behaviors.

A mother said this:

*My only worry is that at puberty he starts with bad behaviors like drug addition and alcoholism I’m so much afraid of that.*

### 3.6 Parent’s coping with their social environment.

A major strategy to help the child cope with its life outside of the family is to inform school. Parents always informed their children’s teachers about the child behavior and its medical causes and discussed about how best to handle the child. In this respect, most parents said they would try to reach a balance between the rules at school and the rules at home.
Coping with family, friends and neighbors proved more difficult. Parents spoke of isolation after their children’s diagnosis of ADHD. They ascribed this isolation to the fact that it is parents who are always blamed when a child behaves abnormally.

An informant said that the attitude of the environment towards her was terrible.

You become totally isolated. Many people think you are a bad parent; you have not paid enough attention in raising your child.

Another mother said she did not even know how to describe the way the environment rejected her, even her close family members like brothers and sisters. Like other parents she said that people in the environment have a very strong opinion of your child.

You are really isolated. People do not come to our house and always said we have to be tough on her, we were always to be blamed.

Some parents lost friends. You do not really go visiting when you have such children because they will always have something to say. The isolation is such that you just have to count on yourself.

For example this mother said:
My brother could say R (that is our oldest daughter, the one without ADHD) can come for a visit but F (that is our daughter with ADHD) we want you to leave her at home because she is always so busy and difficult to handle and very unpredictable.

Nevertheless, some parents spoke of the assistance they received from their own parents, friends and the community. For those parents life went on normally, albeit they did stop visiting friends and relatives because they could not control the behavior of the child outside the home.

There was no change of behavior towards my family, we did not loose any friends, but I do not pay visit to people often because of him.
3.7 Role of the ADHD Association.

Finding one’s way through the health care system and especially learning to cope with the condition and its social consequences for the child, the family and the wider environment is not always easy. In The Netherlands there is a non-governmental association, named Balans, which helps parents who have children with behavioral problems especially ADHD. Parents may receive information concerning this non-governmental association from their family doctors, media and friends.

It found out that few of the parents that I interviewed had attended meetings of the parents’ association even though most of them claimed that they found it helpful to talk to other people and share experiences, tips, and ideas about the up bringing of children. Parents definitely had the experience that other parents with a similar child may understand better the impact of having an ADHD child.

When asked why they did not join the association, the majority of my informants said that they feel they don’t need to do so, they think that they can manage their problem, that they can handle it. As my study was of small scale and explorative, and informants were found mainly through snowballing, it might be that my informants do not form a representative sample. The fact that I needed parents who can speak English fairly well also biased my study to the more educated and socially stronger families. Nevertheless, those parents that did join the association were very positive about this decision.

A mother said this:

I’m a member of a parent association. I found it very helpful. As parents we share our experiences, tips, ideas on how to handle our children. Also a parent with an ADHD child understands the impact of having and raising such a child.

Not joining the association does not preclude seeing its value. Most parents claimed that ADHD is still not well-known in Dutch society and that people have to be informed about the manifestations of ADHD so that it can be diagnosed earlier and appropriate measures can be taken in consideration.
A mother said this:

_I had a colleague who was fired after three months of job and this was the tenth times he was being fired from a job. I knew he had ADHD, but he did not know. He had problems with everybody except me since I understood him and knew how to go about with him. On my return from holidays I was told he was fired._

The association has a task not only in educating the general public about the medical aspects of ADHD but also in changing the negative image of the condition into a more positive one. Some parents believed that people with ADHD are handicapped in some aspects, but in other aspects have assets that other people do not have, such as creativity and sense of humor.
Chapter 4
DISCUSSION

I started my research from the question what role parents play in the diagnosis of ADHD, and how they experience and cope with this condition in Dutch society. In my introduction, I sketched how the concerns of medical and educational professionals converged in the creation of a label that is basically medical, but that is applied on the basis of behavioral and educational problems and that is treated with a combination of medical and behavioral interventions. I argued that the role of parents in this diagnostic process is unclear and that parents usually come to the fore as very much dependent upon teachers and doctors. This study confirmed the very important role of parents in the diagnostic process concerning ADHD. The parents that I spoke to impressed me as very serious observers in the way their children behave and careful weighers of norms of normal and abnormal behavior. I therefore agree with Silver (1992) who says that like teachers, parents should be taken seriously when they bring in a child with school, academic and behavioral problems.

This study confirms that the cooperation between parents and teachers is at the core of the diagnosis of ADHD in children. From my interviews it seems that parents listen carefully to teachers concerning their child’s behavior and its academic performance. Parents emphasized the role of teachers since they are involved in training which helps to bring out this type of behavior and they might be able to diagnose problems earlier than parents. Teachers therefore are valuable resource persons for parents. They can also provide valuable information on help seeking. For example, most teachers are aware about the existence of Balans, the non-governmental organization in The Netherlands that provides information and advice to parents having children with behavioral problems.

Whereas it is usual for ADHD children with high intellectual abilities to go undiagnosed until the secondary school since they have learned how to compensate enough to get by in elementary school (Goldstein: 1992), in this research most of the children were diagnosed in the early age during elementary school. Therefore the teachers that parents spoke of were mainly primary school teachers.
The ideas of parents about ADHD appear to be in concordance with current biomedical views. No doubt the information provided by magazines, the media and teachers and doctors play a role in this high level of knowledge. For parents the most important issue in the etiology of ADHD seems to be its familial or genetic character.

Through my research I have been able to gain some insight in the help seeking processes of parents having children with ADHD. Family doctors are the first professionals that parents see, especially for children born without any complication. The pediatrician sees some children directly since they have been consulting them from birth and regularly at follow up. In most cases, however, the family doctor refers the child to a pediatrician who would try to find out if there is any physical abnormality causing the child to behave abnormally, and if this is not the case the child would thereafter be referred to a child psychiatrist. This specialist, together with the help of a psychologist, parents, teachers and personal observations, then can diagnose ADHD. Normally the child follows several treatments, which are medical, and sometimes psychotherapeutic, while parents and other members of the family undergo family training. Also parents seek for help by reading in magazines, surfing in websites to get more information to handle their ADHD children better. That parents are not fully dependent upon teachers and health professionals is clearly demonstrated by the fact that not all parents choose to treat the child with medication. The main issue is their fear that the drug that is used in treating ADHD might induce long-term side effects.

In general, however, the confrontation with professional viewpoints on ADHD is experienced by parents as beneficial. Parents felt happy after their children were diagnosed as having ADHD because the disorder is labeled, has a name and is recognized medically. The satisfaction was also due to the fact that parents thought a solution could be found from health professionals. The diagnosis of ADHD in their children helped parents to explain the condition and its consequences to their environment and the community in general so that they might be able to deal with the behavior of their children more wisely.

Apart from seeking educational and medical help, parents tried to cope with this situation by talking to friends and attending parent training or counseling. When parents have a child with ADHD or any type of behavioral problems, it is not unusual for the parents to feel guilty or to blame themselves: or they might suspect or experience that the community blames them for
the behavior of their children (see Goldstein, 1992, Rief, 1993). From the literature it is clear
that parent education and support is very helpful for families with ADHD children.

I am deeply impressed by what the parents told me about the social consequences of having a
child with ADHD. This study shows that the presence of an ADHD child in a family can
make life very difficult. Parents described the stress they and the siblings feel. Everything in
the family is centered on the ADHD child. Some parents became a member of the parent
association since it helps them understand their ADHD child better and they have learnt
strategies to cope with the hyperactivity, distractibility, and/or impulsivity that can result in
disruptive behavior. This study confirmed general knowledge that parents and siblings of
ADHD children are more likely to experience psychological distress than are those of normal
children.

All parents having ADHD children were worried about the future of their children. This has to
do with a shift in biomedical knowledge about ADHD, of which parents are aware. Doctors
previously thought that the majority of children would outgrow many characteristics of
ADHD by the time they reach adolescence. At that time parents and teachers were instructed
that if they could just get their child safely through the elementary school years, then ADHD
issues would diminish. It is now clear that as many as seventy percent of ADHD youngsters
will continue to have problems related to attention deficits throughout their adolescence and
into adulthood (Wodrich: 1994). According to Silver (1992), ADHD is both a life disability
since hyperactivity, distractibility and impulsivity are not just school problems; but are life
problems. These behaviors interfere with classroom learning. They also interfere with family
life, peer interactions, and other activities. Fifty percent of children with ADHD will continue
to have this disorder far into their adolescence. Of adolescents with ADHD, it is estimated
that between thirty and seventy percent will continue to have ADHD as adults.
Parents are also anxious about their child’s behavior because they know about the relation
found between ADHD and criminal offences. Most children with ADHD undergo only a
partial remission and are therefore vulnerable to anti-social behavior, substance use disorders,
and mood disorders. Learning problems continue throughout life (Barkley: 1994). Parents are
afraid that their child might exhibit bad behavior like alcoholism and drug addition.
Chapter 5

CONCLUSION

When starting this research on ADHD, I was very excited since I had a different view about what ADHD was. I came into this research with the view that ADHD is a western construct. Being an African medical doctor from the developing world I had not seen children been diagnosed with this disorder. Also when reading the literature I found that parents and teachers are at the forefront of the ‘medicalization’ of the disorder and that pharmaceutical companies in presenting medicines as a solution to academic problems played a role in the prevalence of this diagnosis. In other words, I thought that ADHD was an invention of Western culture to deal with behavioral and educational problems of children.

After completing this study, my ideas about ADHD have changed. ADHD in children is a serious problem in Dutch society. Parents with children having ADHD blame themselves and also feel the community is blaming them for their child behavior and at the end, they stay in their ‘own world’. Parents stay on their own, stop visiting friends and family members. Parents stay away from people because they do not want to hear what people will say about their children, such as ‘you have to be hard on him or her’, ‘you have to punish him’ ectecera. Parents have found solutions concerning the child behavior within the family, but face difficulties when the child is outside the family context.

Parents depend on the biomedical view of the disease and the options for treatment. They all know that ADHD can neither be cured nor prevented. Most parents have developed their own way of coping with the disorder. They all seek for help in the same way such as talking with friends, visiting health professionals. Help seeking might not only consist of finding better ways to cope like giving information to more people, improving the knowledge on the side of teachers, visiting websites ectecera, but also show the more positive side of ADHD. The study shows how important it is that doctors take parents and teachers seriously. The diagnosis of ADHD in children and adolescents often depends on information provided by parents and teachers (Teicher et al., 1996). Parents and teachers depend on doctors who provide medications and guidelines to parents concerning the up bringing of such children.
This qualitative research shows that socio-cultural factors have to be taken into consideration without playing down the seriousness of the problems that families having children diagnosed with ADHD have to face. For the fact is that they have to live in this society and that their condition prevents successful living. In order to accommodate and help parents to better deal with their children diagnosed with ADHD, strategies should take the role and view of parents in the diagnostic process and treatment into account.

Another way to deal with ADHD has recently come from specialists who are encouraging people to think of ADHD not as a disorder, but simply as a different style of learning which when supported can enhance the student’s innate abilities (Goldstein: 1992).

The fact that there are no reports on the incidence and prevalence of ADHD in Africa might be explained by the fact that parents face different problems with their children like famine, infectious disease, shelter, etcetera. Besides other concerns, behavioral disorders such as attention deficit or hyperactivity might not be seen as abnormal by the parents and therefore no help is sought for these behaviors. However, with changing socio-cultural circumstances and the opening up of African communities to the globalizing world, factors determining the success of a person’s life might be shifting as well. When promoting equal opportunities for children through general education, behavioral problems determining educational success also come to the fore.

This study have opened my eyes to the fact that the disorder which I thought was a western construct might be one of the causes of widely acknowledged social problems in my own country: child delinquency and school drop out in children and adolescents in Cameroon in particular and in Africa in general. I have come to believe that on the one hand, parents should be educated to take seriously any behavioral abnormalities in their children and report it to health professionals, that they should work hand in hand with teachers, and furthermore, that if the population in general is informed or educated about the upbringing of children this will help the population to observe differences in behavior, and become conscious of abnormal behavior that, if not dealt with might play a negative role in the future of these children and in the future of the country. On the other hand, Government should reinforce teachers’ curriculums, and provide for the training of more teachers and the building of more schools so that the number of pupils per teacher will be reduced and teachers will be able to attend to them and notice any problematic behavior. Because of the above I have decided to try and organize a campaign of sensibilization about ADHD and if possible to found a non-
governmental organization where parents of children with abnormal behavior can ask for consultation and children might be diagnosed and with the aid of medications and other forms of treatments, ADHD and behavioral disorders can be remedied. In this way I hope to contribute to a normal educational career for these children, that is, that at least they will not drop out of school and will be able to find an orientation in life that is satisfactory for them and their society.
Annex 1

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Annex 2

Interview guidelines for an interview with a key informant (and other health professionals).

1-Background Knowledge about the informant
Can you tell me something about yourself? (Professional information’s)

2- Do you see many parents of children with behavioral problems?

3- Do parents of children have previous knowledge about the disorder?

4- Can you tell me where such parents get information?

5- What are the similarities and differences when you compare your encounter with parents of children having ADHD and parent of normal children?

6- Do you have any ideas about the number of children they have and the position in the family of these children with ADHD?

7- Do those parents have a higher or lower level of education?

8- Before seeking for help do parents try to handle their kid on their own?

9- What are the clinical manifestations of ADHD?

10- In general, what is the treatment of ADHD?

11- How do parents approach their ADHD child?

12- Do you think parent’s approach their ADHD child different than their other non-ADHD children?

13- Are they other things you will like to tell me?