

Parental perception of family functioning in everyday life with a child with ADHD.

## **Introduction**

Attention-deficit/hyperactivity disorder (ADHD) is one of the most common developmental disorders in childhood, with a prevalence of approximately five percent of school-aged children [1]. Those diagnosed with ADHD are a heterogeneous group, but are characterized by symptoms of inattention, hyperactivity and impulsivity as a persistent pattern throughout their life span [2]. The disorder causes impairments of executive neuropsychological abilities; working memory, organization, self-regulation of affect, motivation arousal and internalization and reconstruction of speech. These impairments and the child's behavior may also influence functioning across multiple domains, including family life, school and social relationships [2]. The impairments vary with different persons, with age and with context. Interventions include both the child and the family [3]. Medication often helps the child to focus in school and make positive changes in the child's behavior, although mothers are ambivalent regarding medication [4].

Family studies support a strong familiar nature, and twin studies estimate a heritability of 76%, which implies that a child with ADHD is more likely to have a parent with ADHD [5]. These parents might not have deficits in parenting skills, but their capacity in help-seeking and to maintain and create what they view as a "normal" family environment maybe limited [6]. Mothers of children with ADHD described self-blame in not being a good enough parent [7], concern and guilt for the child's behavior and relief when the child is diagnosed [8].

Parents described mothers as being the active partner in the follow-up of the child in school and regarding health issues [8,9].

Dallos and Smart [10] described how parents' conflict, family dynamics and attachment strategies have a negative influence on children with ADHD. Low paternal involvement and inconsistent discipline have all been associated with ADHD [11]. Parents of children with

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ADHD may have difficulties in maintaining family functioning such as organization and cohesiveness, regardless of available resources and education [12]. To identify the families' difficulties early on and refer the children to a specialist to acquire the ADHD diagnosis, treatment and care may help both the family and the children [13].

In previous qualitative studies the child's behavior, internal resources within the family such as the parents' ability to manage everyday life and external resources such as the support from the network and health services have been found to influence the family functioning [8,9]. It would be of great interest to further investigate aspects of the findings from the qualitative studies in a larger sample.

### ***Aim***

The aim of this study was from the parents' perspective describe and investigate family characteristics in relation to support, the behavior of the child, family functioning and sense of coherence in families with a child with ADHD. A further aim was to explore the predictors of family functioning.

## **Methods**

### ***Design and sample***

A cross-sectional study was performed. The study population was members of the Norwegian ADHD association, and there were 1964 parents (N=1347 mothers, N=617 fathers) who fulfilled the inclusion criterion of being a parent of a child with ADHD aged 15-years-old and younger. The sample size was calculated to be sufficient by consulting a statistician, thereby resulting in 400 mothers and 200 fathers. A drop-out rate of approximately 50% was assumed [14]. Fifty-two parents were excluded due to duplicates, wrong address and do not have a child with ADHD. The sample, randomly chosen, included 354 mothers and 194 fathers. From the group of fathers, 35 mothers responded instead of the fathers. There were no

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statistically significant differences between those 35 mothers and the other participating mothers (n=182) concerning the included variables. Those mothers were therefore included resulting in a response rate of 48.2%, from mothers 82.2% and from fathers 17.8%. One questionnaire from a father was excluded because of an over 50% internal dropout, with the remaining 264 participants including 217 mothers and 47 fathers (Figure I).

*Please insert Figure I about here*

Information given in the members register showed that parents who responded to the questionnaire did not differ significantly from non-responding parents in terms of gender, place of residence and age of the child with ADHD. The data collection took place from February 2013 to June 2013 and a questionnaire was sent by postage mail to the parents, while two reminders were sent in sequences of six weeks.

### ***Measures***

The questionnaire included questions regarding the characteristics of the parents, children with ADHD and the family plus four instruments.

*Parents characteristics* included questions regarding age, gender, marital status (cohabitants/married or single/divorced/widow/widower), education (compulsory school, upper secondary school or college/university), and parents self-reported ADHD-diagnosis (yes, do not know, no).

*Characteristics regarding the child with ADHD* included age, gender and child on medication (yes, no).

*Characteristics regarding the family* included the number of members in the household, the number of children below the age of 18 living at home and place of residence (urban or rural).

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*Support from the health services* included two questions. “To what extent do you experience that your family has been supported by the community health service regarding the child with ADHD?” and “To what extent do you experience that your family has been supported by the specialist health service regarding the child with ADHD?” The response rate ranged from 1=not at all, to 7=to a high degree, with only the anchors defined.

The *Sense of Coherence-13 scale (SOC-13)* was used to measure meaningfulness, comprehensibility and manageability in parents. The scale was conducted by Antonovsky [15]. The short version contains 13 items, e.g. with items such as: “How often has it happened that people whom you have counted on have disappointed you?” and “How often do you have the feeling that there is little meaning in the things you do in daily life?” The items have a seven point scale, with the anchors defined. The sum score is computed by adding all the individual items, with the score ranging from 13 (weakest SOC) to 91 (strongest SOC). The instrument has been validated in other studies [16]. The Cronbach’s alpha coefficient in this study was .86.

*Family Assessment Device (FAD)* measures the general family climate and functioning [17] and in this study the subscale General Functioning was used [18]. The subscale contains 12 statements, including six statements regarding healthy functioning in the family, such as “In times of crisis we can turn to each other for support” and six statements describing unhealthy functioning in the family, such as “Planning family activities is difficult because we misunderstand each other”. The response options ranged from 1=totally agree, to 4=do not agree at all, with the lower the mean score, the greater the family functioning. The instrument is validated in other studies e.g. [19]. The Cronbach’s alpha coefficient in this study was .90.

The *Strengths and Difficulties Questionnaire (SDQ)* (parent version) rates the child’s behavior and covers five dimensions: Emotional problems, conduct problems, hyperactivity, peer-

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problems and pro-social behavior [20]. This instrument contains of 25 statements, including examples such as: “Considerate of other people's feelings”, “Constantly fidgeting or squirming” and “Picked on or bullied by other children”. Each statement has three response alternatives; “not true”, “somewhat true” or “certainly true”. The sum score is calculated by adding all the statements and ranging from 0-50, with the lower score the better. The instrument has also been validated in other studies [21]. The Cronbach’s alpha coefficient in this study was .78.

The *Social Cohesion and Support Index (SCS)* measures the individual experience of social support and integration in social networks, which was conducted and related to Cobb’s [22] three classifications of information [23]. The index has four questions; (a) “Somebody cares, loves, and respects you”; (b) “Somebody can understand and confirm your intention”; (c) “Somebody can give assistance when you are sick or otherwise in need”; and (d) “That one belongs to a group with shared interests and mutual trust in each other”. The questions are answered on a five point scale, with five being high perceived social support and the results are presented in a mean score of the four items. The index has been used and validated in Norwegian population studies [24]. The Cronbach’s alpha coefficient was in this study .78. The questionnaire was pilot tested for clarity with 10 parents in the Norwegian ADHD association and was considered as being relevant and not offensive, and no changes were made.

### ***Ethical considerations***

The study was approved by the Regional ethical committee for medical and health research in Norway. During the entire research process the researchers followed ethical research principles according confidentiality, nonmaleficence and justice. The member lists of the Norwegian ADHD association were blinded, a randomized sample was drawn and an

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employee at the Norwegian ADHD association sent the questionnaire to the parents with an information letter regarding confidentiality and voluntariness.

### *Statistical analysis*

Statistical analyses were performed using IBM Statistics SPSS, version 20. Descriptive statistics with frequencies, percentages, means and standard deviations were used.

Comparisons between groups were analysed using Pearson's Chi-square tests, independent sample t-tests and one-way analysis of variance (ANOVA). A post hoc test Tukey HSD was used to find out where the difference among the groups occurred. A standard multiple regression analysis was performed with FAD as a dependent variable, together with parents' gender, age, marital status, self-reported ADHD, SOC, SCS, medication of the child, SDQ and support from the health services as independent variables [14]. The internal consistency was measured through the use of Cronbach's alpha.

Pearson's Chi-square tests were run to compare the respondent study sample with the non-respondent. All tests were two-tailed with a p-value <.05.

## **Results**

### *Description of the parents, the children with ADHD and the families*

The majorities of the parents were cohabitating or married. They lived in both rural and urban areas, and 50.8% had a college or university education, while 15.2% had self-reported ADHD. The mean age of the children with ADHD was 12, most of the children were boys and most of the children were on medication for ADHD. Comparisons between men and women revealed only one statistically significant difference, namely that the men were older than the women ( $t=3.98$ ;  $p=.000$ ) (Table I).

*Please insert Table I about here*

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Social support (SCS) was reported with a mean score of 3.9 and the parents' SOC was 62.85 and the parents rated their child's behavior (SDQ) with a mean score of 23.39, the mean score of the number of family members was 4.20 and the mean score of the number of children below the age of 18 living at home was 2.17. Family function (FAD) was reported with a mean score of 1.98.

### *Comparing subgroups*

Independent-sample t-tests were conducted to compare the parents' marital status, educational level, and the children's gender and medication, and place of residence, in relation to SOC, SCS, SDQ and FAD. Married/cohabitants had a significantly stronger SOC ( $m=63.48$ ,  $SD=11.23$ ) compared to single parents ( $m=59.45$ ,  $SD=8.24$ ), ( $t=2.67$ ;  $p=.009$ ). Parents who lived in urban areas rated their children significantly lower in SDQ ( $m=22.27$ ,  $SD=6.09$ ) compared to those living in rural areas ( $m=24.56$ ,  $SD=6.37$ ), ( $t=2.93$ ;  $p=.004$ ).

There were statistical significant differences between parents with a child medicated for ADHD and parents with children who did not use medication (Table II).

*Please insert Table II about here*

The parents in families with children medicated for ADHD were more satisfied with social support and integration in social networks (SCS), and they rated their child's behavior (SDQ) as less problematic and with better family functioning (FAD) than parents in families with children not on medication.

Moreover, one-way between-groups analyses of variance (ANOVA) were conducted to explore the impact of the parents' self-reported ADHD with regard to SOC, SCS, SDQ, and FAD (Table III).

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*Please insert Table III about here*

There were statistical significant differences regarding SOC and FAD and post-hoc comparisons using the Tukey HSD test showed that the parents with self-reported ADHD had a weaker SOC, and rated FAD as less favorable compared to those reporting not having ADHD.

### ***Predictors of family functioning***

A standard multiple regression analysis was run to investigate the impact of the independent variables (parents' gender, age, marital status, self-reported ADHD, SOC, SCS, medication of the child, SDQ and support from the health services) with respect to the dependent variable (FAD). The combination of the independent variables explained 46.2%, of the variation in the dependent variable FAD (Table IV).

*Please insert Table IV about here*

Parents' age, SOC, SCS, SDQ and support from the community health services showed a statistically significant impact on the dependent variable (Table V). SOC, SCS and support from the community health services had a positive effect on family functioning.

*Please insert Table V about here*

## **Discussion**

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The findings showed the parents having ADHD themselves were the most vulnerable as they had a low sense of coherence (SOC) and poorer family functioning (FAD) than the other parents. Families with children medicated for ADHD reported less behavioral problems (SDQ), a better family functioning (FAD) and more social support (SCS). The combination of independent variables explained 46.2%, of the variance in FAD, with the parents' SOC, SCS and the children's' SDQ described the most.

The parents in the present study reported a better family functioning than a study by Foley [12], who also measured family functioning with FAD in families with children with ADHD. Foley [12] further concluded that parents of children with a diagnosis of ADHD had more difficulties maintaining family organization and cohesiveness.

The parents' sense of coherence (SOC) explained most of the variation followed by support from the social network (SCS) and the child's behavior (SDQ). Parents have described their concern and are seeking tools and structure to help manage their child with ADHD in everyday life [8,9]. Some families used a white-board to structure their weekly activities [9]. The use of external resources may help them to make their life predictable such as with the social support in the ADHD association, and with relatives and friends which may strengthen their SOC and promote the balance in demands, thereby leading to more manageability [15]. Families with better family functioning (FAD) experienced more support from the community health services, which highlights need of available professionals in the community health services. Support and follow-up at school, as well as other interventions such as parents management training [11], and the support from voluntary groups in the community have been shown to be important to family functioning [7,8]. These interventions require multidisciplinary collaboration [25].

In the present study there were only age differences when comparing mothers and fathers. However, other studies have described a difference in mothers tending to worry, whereas the

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fathers adopted a wait and see strategy [8,9]. Yet others show that mothers tend to be more responsible in the follow-up of the child and report an increase in maternal distress in families with children with ADHD [26].

The parents reported a stronger SOC compared to a Swedish study of the parents of children with autism [27], though the parents in the current study reported a lower SOC than a control group with parents of healthy children in the study by Olsson and Hwang [27]. Having a child with impairment such as ADHD is a chronic stressor, and stress influences the parents' sense of coherence. The parents with self-reported ADHD and a weak SOC may be more vulnerable than parents without ADHD. Furthermore, we have not found any other studies measuring parents' self-reported ADHD and SOC, though in a longitudinal study with adults who had ADHD, a strong SOC was associated with less ADHD symptoms in early adulthood [28]. Parents with ADHD in the present study also reported a FAD higher than other parents, which may indicate more problems in the family.

Children on medication had less problematic behavior and the parents reported better social support and family functioning compared to non-medicated children. The mothers feeling of ambivalence towards the medication for the child are described in other studies [4]. Solheim and Wichstrøm [29] describes that 7.8% of the child population (aged 4 years) rate within the highest SDQ (12-40). This reflects the need for support and supervision that these parents need, both from their social network [8] and from professionals such as the public health nurse [25].

There are some limitations to this study. First, in spite of two reminders, the response rate was only 48%, which may lead to a response bias [14], however the dropout analysis showed no differences between the responding and the non-responding parents regarding the parents'

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gender, the child's age and the place of residence. The reasons for not responding are not known and a low response rate is not uncommon in comparable studies [e.g 30], but those who did not participate may have been more strained compared to those who did. Second, the data are self-reported, which may lead to under- or over-reporting the families' strains or manageability. Third, the questionnaire was answered by parents and other family members, such as the children with ADHD, and their siblings may respond differently from their parents. This calls for research with all family members. Fourth, some mothers responded instead of their husbands, which led to a lower response rate from fathers. This may put into question whether the fathers' in the sample were representative of the entire population, and the lack of differences between parents regarding gender may support this question. Last, the parents were members of the ADHD association, which may lead to elite bias [14], or that the parents who are not members could have less problems with their ADHD children. Families living in rural areas may have less knowledge of- and availability to the organization according to where they live. Parents living in rural areas rated their children's behavior as more problematic than those living in urban areas. This may reflect the parents' frustration concerning their child being more observed and controlled in a rural society, as well as a lack of other parents with the same experience to discuss their family matters with. The results may not be able to generalize to families not members of an ADHD association.

## **Conclusions and further research**

A strong sense of coherence, social support and support from community health services were all strongly associated with a positive effect on family functioning. Parents with ADHD reported a weaker sense of coherence and poorer family functioning than parents without ADHD. This knowledge may be useful and taken into account when planning support for these families. Further research could be carried out with all family members with focus on

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internal and external factors influencing family functioning. Longitudinal research studies are needed regarding factors that influence family functioning.

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### **Conflicts of interest**

None declared.

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