

## Assessing the Quality of Life of Mothers of ADHD Children and Comparison of Quality of Life with Mothers of Children with Down Syndrome

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### Abstract:

*The aim of the present study was to assess the Quality of Life of the mothers of children with ADHD. The WHOQOL-BREF and the Conners Parent Rating Scale were used for this purpose. The sample was collected from 22 mothers of ADHD children. The Mothers' Quality of Life was assessed on four domains – Physical health, Psychological, Social relationships, and Environmental. Majority of the mothers reported their overall quality of life as “good” and general health as “satisfied”. Among the domains of the Quality of Life Scale, the mothers had highest quality on social relationships and lowest quality on physical health, which is in line with the normative sample. It was hypothesized that the severity of ADHD would be negatively correlated with the quality of life. It was found that there was a mild to moderate negative correlation between the two variables. This implies that the greater the severity of ADHD in children, the lower would be the quality of life of the mothers. Another hypothesis was that Quality of life of mothers of Down Syndrome children (N=25) would be better than that of ADHD children (N=22). However, no significant difference was found between the quality of Life of mothers of ADHD and Down Syndrome children.*

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**Key words:** quality of life, mothers of children with ADHD, mothers of children with Down Syndrome

## Introduction

Attention-deficit/hyperactivity disorder (ADHD) is a chronic condition that affects millions of children and often persists into adulthood (Mayo Clinic Staff, 2011). It is a disorder in which a person is unable to control behavior due to difficulty in processing neural stimuli, accompanied by an extremely high level of motor activity. ADHD can affect children and adults, but it is easiest to perceive during schooling. A child with ADHD may be extremely distractible, unable to remain still, and very talkative (MedicineNet.com, 2012). Children with ADHD also may struggle with low self-esteem, troubled relationships and poor performance in school (Mayo Clinic Staff, 2011).

ADHD was first described by George Still in 1902. He called it 'morbid defect of moral control'. It's also been called minimal brain damage (1930), minimal brain dysfunction (1960), hyperkinetic reaction of childhood (1968), attention deficit disorder (ADD) with or without hyperactivity (1980). Since 1987, it has been known as ADHD or Attention Deficit Hyperactivity Disorder (Coghill, 2007).

There are three different types of ADHD, depending on which symptoms are strongest in the individual:

- *Predominantly Inattentive Type:* It is hard for the individual to organize or finish a task, to pay attention to details, or to follow instructions or conversations. The person is easily distracted or forgets details of daily routines.
- *Predominantly Hyperactive-Impulsive Type:* The person fidgets and talks a lot. It is hard to sit still for long (e.g., for a meal or while doing homework). Smaller children may run, jump or climb constantly. The individual feels

restless and has trouble with impulsivity. Someone who is impulsive may interrupt others a lot, grab things from people, or speak at inappropriate times. It is hard for the person to wait their turn or listen to directions. A person with impulsiveness may have more accidents and injuries than others.

- *Combined Type*: Symptoms of the above two types are equally present in the person (Charlie, 2012).

## Symptoms

It is normal for children to have trouble focusing and behaving at one time or another. However, children with ADHD do not just grow out of these behaviors. The symptoms continue and can cause difficulty at school, at home, or with friends.

A child with ADHD might:

- have a hard time paying attention
- daydream a lot
- not seem to listen
- be easily distracted from schoolwork or play
- forget things
- be in constant motion or unable to stay seated
- squirm or fidget
- talk too much
- not be able to play quietly
- act and speak without thinking
- have trouble taking turns
- interrupt others

Some children with ADHD also have other illnesses or conditions. For example, they may have a learning disability, Oppositional defiant disorder, Conduct disorder, Anxiety and depression, Bipolar disorder and Tourette syndrome. ADHD also may coexist with a sleep disorder, bed-wetting, substance abuse, or other disorders or illnesses (n.a., 2010).

## Causes

Scientists are not sure what causes ADHD, although many studies suggest that genes play a large role. Like many other illnesses, ADHD probably results from a combination of factors. In addition to genetics, researchers are looking at possible environmental factors, and are studying how brain injuries, nutrition, and the social environment might contribute to ADHD.

*Genes* - Results from several international studies of twins show that ADHD often runs in families. Researchers are looking at several genes that may make people more likely to develop the disorder. Children with ADHD who carry a particular version of a certain gene have thinner brain tissue in the areas of the brain associated with attention

*Environmental factors* - Studies suggest a potential link between cigarette smoking and alcohol use during pregnancy and ADHD in children. In addition, preschoolers who are exposed to high levels of lead, which can sometimes be found in plumbing fixtures or paint in old buildings, may have a higher risk of developing ADHD.

*Brain injuries* - Children who have suffered a brain injury may show some behaviors similar to those of ADHD.

## Treatment

The most common type of medication used for treating ADHD is called a "stimulant." Although it may seem unusual to treat ADHD with a medication considered a stimulant, it actually has a calming effect on children with ADHD. Many types of stimulant medications are available. A few other ADHD medications are non-stimulants and work differently than stimulants. For many children, ADHD medications reduce hyperactivity and impulsivity and improve their ability to focus,

work, and learn. Medication also may improve physical coordination.

Current medications do not cure ADHD. Rather, they control the symptoms for as long as they are taken. Medications can help a child pay attention and complete schoolwork. It is not clear, however, whether medications can help children learn or improve their academic skills. Adding behavioral therapy, counseling, and practical support can help children with ADHD and their families to better cope with everyday problems.

Different types of psychotherapy are used for ADHD. Behavioral therapy aims to help a child change his or her behavior. It might involve practical assistance, such as help organizing tasks or completing schoolwork, or working through emotionally difficult events. Behavioral therapy also teaches a child how to monitor his or her own behavior. Learning to give oneself praise or rewards for acting in a desired way, such as controlling anger or thinking before acting, is another goal of behavioral therapy. Parents and teachers also can give positive or negative feedback for certain behaviors. In addition, clear rules, chore lists, and other structured routines can help a child control his or her behavior. Therapists may teach children social skills, such as how to wait their turn, share toys, ask for help, or respond to teasing. Learning to read facial expressions and the tone of voice in others, and how to respond appropriately can also be part of social skills training (NIMH, 2012).

## **ADHD and quality of life**

The World Health Organization (WHO) defines “quality of life” as the perception that individuals have of their position in life within their cultural and value systems, their objectives, expectations and concerns.

Having an ADHD child affects the well-being and the

overall quality of life of the parents socially, financially, emotionally, etc. to a greater extent, as compared to having a normal child. This effect is seen more in mothers of ADHD children, who are often the primary caregivers and the ones spending more time with the children.

Edwards, Schulz, and Long (1995) mentioned that families of children with ADHD have been reported to have difficulties in various aspects of functioning. According to Fischer (1990), studies examining broad areas of functioning have found that parents of children with ADHD report experiencing significantly more stress, feelings of incompetence, and marital discord than parents of children without ADHD.

Xiang, Luk and Lai (2009) conducted a study to assess the quality of life in parents of children with attention-deficit-hyperactivity disorder in Hong Kong. Seventy-seven parents of children with ADHD were consecutively selected and the sociodemographic and clinical characteristics of the parents and their children were assessed. Compared with the general population in Hong Kong, significantly lower scores in physical, psychological, social and environmental QOL domains were found in the parents of children with ADHD. On multivariate analysis, for the children with ADHD, the severity of emotional and hyperactivity/inattention symptoms, and having a comorbid pervasive developmental disorder were significantly correlated with one or more domains of QOL.

Baker and McCal (1995) compared reports of parenting stress among mothers of children with ADHD, mothers of children with learning disabilities and mothers of non-referred children. Results showed that parenting stress was highest for mothers of children with ADHD. Increased parenting stress was associated with child characteristics and, in particular, with externalizing behavior problems.

Peters and Jackson (2009) explored the perceptions and experiences of mothers parenting a child with attention deficit hyperactivity disorder. Data was collected from 11 mothers of

children with attention deficit hyperactivity disorder via in-depth interviews. Analysis was completed by listening for self-evaluative statements, paying attention to meta-statements and by identifying both consistencies and incongruities within participant's narratives. Dominant issues identified were: It's been 10 years of being on edge: The caring responsibility as overwhelming; If I had my time over again, I wouldn't tell the truth: Stigmatized, scrutinized and criticized; What have I done? What did I do? How come I've got this child: Guilt and self-blame and He doesn't stand a chance: Mother as advocate. Mothering a child with attention deficit hyperactivity disorder is stressful and demanding, and mothers felt marginalized.

According to Klassen, Miller & Fine (2004), parenting stress was increased when child behaviors, such as those associated with ADHD, increased in frequency and severity. The problems of children with ADHD have a significant impact on the parents' emotional health and parents' time to meet their own needs, and they interfered with family activities and family cohesion.

Mash & Johnston (1983) found that depression and low self-esteem in a parent were related to children having ADHD. Building on the model that Mash developed, Vitanza & Guarnaccia (1999) concluded that there is a significant correlation between a mother's low self-esteem and maternal depression in the context of parenting children with ADHD.

## **Methods**

The aim of the present study was to assess the Quality of Life of the mothers of children with Attention Deficit Hyperactivity Disorder (ADHD). The WHOQOL-BREF consisting of 26 items was used for this purpose.

Hypothesis 1: The severity of ADHD would be negatively correlated with the quality of life.

Hypothesis 2: The Quality of life of mothers of Down

Syndrome children would be better than that of ADHD children.

### **Sample**

The present study was conducted on the mothers of ADHD children (N=22) in the age range of 4 to 14 years. Sample was also collected from mothers of Down's syndrome children (N=25) in the age range of 1 to 23 years, for comparison. Purposive sampling was done, in which the characteristics and criteria for the sample was predetermined and kept in mind while collection of data.

### **Instruments**

Basic demographic and history form:

DSM-IV TR criteria for ADHD

Conners' Rating Scales (CRS): The CRS is a widely used instrument designed for use by parents (Conner's Parent Rating Scale; CPRS) to assess ADHD in children ages 3-17 (Conners, Parker, Sitarenios, & Epstein, 1998). The CPRS consists of 45 items, used to assess six different groups of childhood problems, including inattention, hyperactivity/impulsivity.

WHOQOL-BREF: The World Health Organization Quality of Life is the original questionnaire developed by the WHO and contains one hundred questions. The assessment tool used in the present study was the summarized Portuguese version, of the WHOQOL-BREF (Appendix 1). It comprises 26 questions assessing four domains: the physical, psychological, social and environmental domains.

### **Scoring**

*Conners Parent Rating Scale*: This scale consisted of 45 items scored on a Likert scale from 0-3. The response scores obtained on the questionnaires were transferred to the scoring grid, where the scores for each dimension were added vertically to



obtain the raw scores on each dimension. These raw scores were then converted into T scores for each dimension.

*WHOQOL-BREF*: The scale consisted of 26 items which were all scored as a Likert scale ranging from 1 to 5 with one item having reverse scoring. This will give the raw score for all the four domains. These raw scores are then converted into transformed score using the following formula:

$$\text{transformed score} = \frac{\text{actual raw score} - \text{lowest possible raw score}}{\text{possible raw score range}} \times 100$$

Where “actual raw score” is the score obtained by summation; “lowest possible raw score” is the lowest possible value that could occur through summation & “Possible raw score range” is the difference between the maximum possible raw score and the lowest possible raw score.

Transformed scores were in the range of 0-100 and assessment was done with this score only.

## Results

**Table 1: Distribution of results of the overall quality of life of mothers of children with ADHD.**

Response	Percentage of Mothers
Very good	13.63
Good	45.45
Moderate	27.27
Poor	4.54
Very poor	9.09

**Table 2: Distribution of results of the quality of health of mothers of children with ADHD.**

Response	Percentage of Mothers
Very satisfied	9.09
Satisfied	45.45
Moderate	18.18
Dissatisfied	27.27

Very dissatisfied	0
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**Table 3: Distribution of the results of the questionnaire on Quality of Life (WHOQOL-BREF) answered by the mothers of ADHD children.**

Domain	Mean (ADHD)	SD (ADHD)	Mean (DS)	SD (DS)
Physical health	58.76	14.19	56.99	18.23
Psychological	62.11	16.21	68.16	19.61
Social relationships	71.97	16.17	70.99	24.19
Environmental	66.62	14.48	66.75	22.51

**Table 4: Correlation values (r) between severity of ADHD (Inattention and Hyperactivity) and Quality of Life dimensions.**

DIMENSIONS	D1	D2	D3	D4
Inattention	-0.15	-0.21	-0.12	-0.009
Hyperactivity	-0.11	-0.25	-0.22	-0.03

**Table 5: Significance of difference between the Quality of Life of mothers of ADHD and Down syndrome children.**

Domain	t value	Significance
Physical health	0.37	NS
Psychological	1.14	NS
Social relationships	0.16	NS
Environmental	0.02	NS

## Discussion

The aim of the present study was to assess the quality of life of the mothers of the children with ADHD. It was hypothesized that the severity of ADHD would be negatively correlated with the quality of life. Another hypothesis was that Quality of life of mothers of Down Syndrome children (N=25) would be better than that of ADHD children (N=22). The WHOQOL-BREF and the Conners Parent Rating Scale was used for this study.

As is evident from Table 1, majority of the mothers reported their overall quality of life being “good” (45%), followed by response of “moderate” (27%), then “very good” (13%), then “very poor” (9%), and the least percentage of mothers gave the response as “poor” (4%).

Also, it can be seen from Table 2 that 45% mothers were

“satisfied” with their general health, 27% were “dissatisfied”, 18% were “neither satisfied nor dissatisfied”, and only 9% were “very satisfied” with their general health.

From Table 3, it can be seen that the mothers of ADHD children reported their quality of life as being highest in the social relationships domain (M=71.97). This can be because of the fact that in India, which is considered a collectivistic country, social relationships and connections are highly valued. Social support is considered a highly important aspect in the functioning and lives of people. It is a major way not only to share ones happiness, but is also a means to give vent to ones feelings of sadness, hopelessness or despair experienced, as in the case of mothers of ADHD children.

Also, the mothers rated their quality of life being lowest in the physical health domain (M=58.76). This can be attributed to the fact that the constant running around the child, trying to correct his behaviours every time, making him forcibly sit quietly to start his homework or engage in other activities, physically dealing with their tantrums; takes a toll on the physical health of the mothers of ADHD children. During data collection, many mothers reported having frequent headaches, backaches, lack of energy for other tasks and feeling easily fatigued. Xiang, Luk and Lai (2009) found that, compared with the general population in Hong Kong, significantly lower scores in physical, psychological, social and environmental QOL domains were found in the parents of children with ADHD.

From Table 4, it can be seen that there is a mild negative correlation between the severity of inattention and hyperactivity in children, and the quality of life of mothers. In fact, there was a moderate negative correlation ( $r = -0.25$ ) between hyperactivity and the psychological domain of quality of life. Thus, the hypothesis stands proven. This means that greater the severity of ADHD in children, the lower will be the quality of life of the mothers.

As is evident from Table 5, the Quality of life of mothers

of ADHD children (N=22) was also compared with the mothers of Down Syndrome (N=25) children. No significant difference was found between the means implying that quality of life of mothers of both disabilities is not really different. Thus, the second hypothesis is disproved. Similar result was found in a research by Ravindranan & Raju (2008), in which they found no significant difference in the quality of life of parents of Autism, ADHD, Down Syndrome, LD, and MR. This shows that the quality of life of parents of children with special needs cannot be differentiated on the basis of the category of disability.

Since the sample size was small (<30), generalizability of the results is an issue. Also, some biases on part of the respondents like social desirability and acquiescence might have also affected the results of the study.

## **Conclusion**

From the findings of the present study, it can be concluded that the majority of mothers of ADHD children reported their quality of life to be “good” and being “satisfied” with their general health. This could be because of the fact that these days there are various medications and behavioural modification treatments available to curb and control the undesirable symptoms of ADHD, which leads to a better quality of life for the parents. In terms of the domain of quality of life, the mothers scored the highest on social relationships and lowest on physical health, which is similar to the normative population.

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