

Original Research Article

Quality of life, perceived stress and caregiver burden in mothers of children with childhood psychiatric disorders in Kerala, India

Karuna Sandra Thomas¹, Chitra Venkateswaran^{1*}, Ashwin Varghese Alexander²

¹Department of of Psychiatry, Believers Church Medical College, Kuttapuzha PO, Thiruvalla, Kerala, India

²Department of Radiodiagnosis, Believers Church Medical College, Kuttapuzha PO, Thiruvalla, Kerala, India

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*Correspondence:

Dr. Chitra Venkateswaran,

E-mail: chitven@gmail.com

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ABSTRACT

Background: Common childhood psychiatric problems like attention deficit hyperkinetic disorder (ADHD), Pervasive developmental disorder (PDD) and learning disability (LD) often co-exists with each other and form a constellation of behavioural manifestations that require extra attention from the caregivers. Having a differentially-abled child is challenging and most parents have to learn to restructure their lives around that of the child. There is a difference in the attitudes of both the parents as far as parenting a disabled child is concerned. Mothers often shoulder the primary caregiving role however the psychological costs borne by women go unrecognized. The study aims to assess the care giver burden (BOC) and perceived stress (PS) and quality of life (QOL) in mothers of children with ADHD, PDD and LD.

Methods: It was a cross-sectional study with 336 child mother pairs. The mothers were asked to rate their burden and stress symptoms on the perceived stress scale and Burden of care scale. The mothers were also asked to rate their quality of life on the quality of life scale.

Results: The mean PS score was highest in the PDD group. The mean BOC was lowest in the LD group. The QOL score was highest in the LD group. There is statistically significant difference in the PS, BOC and QOL scores among the three groups.

Conclusions: There is a hidden lacuna of psychological stress in mothers of children with common psychiatric problems. The study also establishes that these mothers have poorer quality of life. It is necessary to address these psychological issues of the mother at every visit and equip them with coping strategies so that they can look after both themselves and their special needs child.

Keywords: Attention deficit hyperkinetic disorder, Caregiver burden, Learning disability, Maternal stress, Pervasive developmental disorder, Perceived stress, Quality of life

INTRODUCTION

Childhood psychiatric problems are being diagnosed more frequently due to the increased awareness programs in schools and among parents. Common among them include attention deficit hyperactive disorder (ADHD), pervasive developmental disorder (PDD) and learning disability (LD). These disorders often co-exist with each other and form a constellation of clinical spectrums with varying levels of behavioral manifestations that require

extra attention from the caregivers.^{1,2} Most adults anticipate the birth of a wanted child with joy and happiness. There are expectations of the child's appearance and personality and of themselves as parents. Indian parents often have a very hand on approach and plan about the child's education, career and future. It is indeed a devastating blow for them to know that their child might not have a normal developmental trajectory. Adapting their hopes to match the actual reality of the child is often stressful. The stark discrepancy between the

imagined parenting experience and the reality of caring for a child with a disorder may lead to intense disappointment and disillusionment.^{3,4}

Having a differentially-abled child is challenging and often provokes a disequilibrium in the whole family.⁵ One of the more stressful adjustments parents of children with a behavioral disorder have to make is the restructuring of daily life around the needs of the child. Adjusting to the temper tantrums and outbursts of the child, getting used to their erratic sleeping and eating patterns and often finding an effective communication strategy with a child is a herculean task.⁶ Parents often have little time or no “personal time”, to explore their own needs, have decreased marital intimacy, increased conflicts and curtailed employment opportunities.⁷⁻⁹ Parents might also harbor negative feelings towards their own siblings, have decreased interaction with neighbors and relatives. This isolation and lack of adequate social support can lead to increased stress levels in the parents. As the child grows up, aggression, sexuality, and a sense of independence increase without the skills for self-management which then becomes a huge concern for the parents. Siblings may leave home for higher education, creating a higher burden of care for parents who have previously relied on their help. The aging of grandparents who may have been a source of support may also lead to less support and greater burden on the parents.

It has been seen that there is a difference in the attitudes of both the parents when disabilities are present in their child and it tends to be on two ends of a spectrum. Mothers reduce their workplace commitments, while fathers withdraw from family and invest more in their jobs. The fathers’ chronic absence increases the mothers’ caregiving burden and stress.^{10,11} Chronic stress on these mothers can lead to “feelings of being overwhelmed” and parental psychopathology like depressive or anxiety disorders which can further lead to poor parenting, setting up a vicious cycle. The stress of parenting a differentially abled child may be worsened by lack of coping skills, stigmatization, decreased social and spousal support, and lower socioeconomic status.¹²⁻¹⁴ Traditionally, women have been attributed primary responsibility for family work in most societies. Thus, women continue to be ascribed the primary caring role of the child and is expected to still carry the bulk of family work alongside. The psychological costs borne by women go unrecognized. In view of the apparent increased rates of distress in mothers of children with psychiatric conditions, this study was undertaken to identify the hidden lacunae of caregiver burden and perceived stress in the mothers of children with ADHD, PDD and LD. The study also aimed to assess the quality of life of these mothers.

METHODS

This was a cross-sectional study of 336 mothers with children with common childhood psychiatric disorders

including (ADHD, PDD and LD), who attended the outpatient services of the department of psychiatry at a tertiary level teaching hospital in Kerala. It was a single interview study. A total of 336 child- mother pairs were consecutively selected and interviewed between September 2012 and August 2014. The study design was approved by the institutional ethics committee. The participants were briefed about the study in the local language and written informed consent was taken before the interview was commenced. Confidentiality was maintained using unique identifiers.

Inclusion criteria

- Those who had children with ADHD, PDD and LD and gave written consent to complete the interview.

Exclusion criteria

- Participants with a history of psychiatric illness or with a history of any chronic disabling condition
- Participants who were primary caregivers to other children or family members with psychiatric disorders or other chronic illness
- Participants whose husbands who were alcohol dependent.

Each interview was completed in a single sitting and lasted for about an hour. Primary information and socio-demographic data were first collected with a specifically designed information tool sheet. The participants were also assessed for the features of anxiety or depression based on the international statistical classification of diseases-10 research guidelines in the first part of the study published elsewhere. Care giver burden and associated stress was assessed with the burden of care scale and perceived stress scale respectively. The quality of the mother’s scale was also assessed with the WHO quality of life scale.

Care giver burden scale

A 22-question formal scale devised and standardized to measure the burden of care (BOC) in the life of the caregiver. The burden dimensions that are assessed are - the impact of having a mentally ill patient in the family on care givers leisure and social life, occupational and mental health, financial situations, family interactions, use of psychoactive substance, effect on other people of the house, effect on other children, stress, stigma concern shame guilt and global burden.¹⁵ The scale has an internal consistency of 0.93 (Cronbach’s alpha) and a test-retest reliability of 0.89. The validity of the scale correlated against burden assessment scale.¹⁶ The Malayalam version of the tool was used in the study.

Perceived stress scale

The perceived stress scale (PSS) measures the degree to which situations in one’s life are appraised as stressful. It

measures the degree to which people perceive that their demands exceed their ability to cope. PSS is one of the more widely used psychological instruments for measuring nonspecific stress. It helps in analyzing the “stressfulness” of the situation. The scale includes a number of direct queries about current experienced stress. The items are easy to understand and the response alternatives are simple to grasp. The PSS has an internal consistency of 0.84 (Cronbach’s alpha) and a test–retest reliability of 0.85. The classical version of the tool after translation was used in the study.

Quality of life scale

Quality of life (QOL) scale is a psychological assessment instrument which is based on a comprehensive theory of self-perceived quality of life and provides a multifaceted measurement of health-related aspects of wellbeing. It is an instrument of choice for monitoring quality of life in the population. A QOL scale can provide such a comprehensive measurement. The scale consists of 3 axes: subjective wellbeing, positive and negative effects and fulfillments of needs. Thus, it globally predicts the quality of life as perceived by the care giver. The WHO QOL BREF has an internal consistency of 0.93 (Cronbach’s alpha) and a test-retest reliability of 0.95. The Malayalam version of the WHOQOL-BREF scale was used in the study.

Statistical analysis

Mean and standard deviation of perceived stress, burden of care, and quality of life scores of mothers of children with ADHD, PDD and LD was computed and statistically tested for their significance by applying the chi square test. t-test and regression analysis was done to see what variables affect perceived stress, burden of care, and quality of life scores. $p < 0.05$ was considered statistically significant. Statistical analysis was done using IBM SPSS Statistics version 20 for Windows (SPSS Inc., Chicago, IL, USA).

RESULTS

336 child-mother pairs were included in this study of which 40% of the children had ADHD, 30% had PDD and 29% were diagnosed with LD. Demographic details of the child-mother pairs has been described in Table 1. In the first part of the study, the mothers were evaluated for psychological issues. 35% of the mothers had anxiety, 37% of the mothers had depression and 11% had mixed anxiety and depression. Statistical significance of PS, BOC and QOL score in the three different groups (ADHD, LD and PDD) was estimated and is as shown in Table 2. The mean PS score was highest in the PDD group. BOC scores were almost similar in the ADHD and PDD groups and lowest in the LD group. The QOL score was highest in the LD group. There is statistically significant difference in the PS, BOC and QOL scores

among the three groups as seen in Table 2. Analysis of the mother’s diagnosis and the PS score showed that there were statistically significant differences in the perceived stress score based on the mother’s diagnosis. There were also significant differences in the BOC and QOL in mothers with moderate depression and no clinical diagnosis. There were significant differences in the PS score, BOC and QOL among the different variables as described in Table 2.

Table 1: Demographic details of the mother-child groups.

Parameter	Number	Percentage
Childs diagnosis		
ADHD	135	40.17%
PDD	102	30.35%
LD	99	29.46%
Gender of the child		
Male	206	61.3%
Female	130	38.6%
Age group of the child		
3-8 years	110	32.73%
8-13 years	178	52.97%
13-18 years	48	14.28%
Dual diagnosis		
Neurological	200	59.52%
Mental health	151	44.94%
Birth order		
1	268	79.76%
2	61	18.15%
3	5	1.48%
4	2	0.59%
Socio-economic status		
Lower	27	8.03%
Middle	185	55.05%
Higher	124	36.90%
Type of family		
Nuclear	229	68.15%
Joint	107	31.84%
Qualification of the mother		
<10 th grade	1	0.29%
10 th grade pass	90	26.78%
12 th grade pass	212	63.09%
Degree	32	9.52%
Post graduate	1	0.29%
Years since diagnosis of the child		
<1 year	94	27.97%
1-5 years	194	57.73%
>5-10 years	46	13.69%
>10 years	2	0.59%
Maternal diagnosis		
Anxiety	119	35.41%
Mild depression	89	26.4%
Moderate depression	35	10.41%
Mixed anxiety depression	38	11.3%

Table 2: Factors associated with perceived stress, care giver burden and quality of life scores.

Factors	n	Perceived stress Mean±SD	Caregiver burden Mean±SD	Quality of life Mean±SD
Mothers diagnosis				
Mild depression	89	18.865±1.189	38.056±7.505	69.741±12.523
Moderate depression	35	22.257±1.224	40.257±6.848	66.657±15.068
p value		<0.0001	0.14	0.25
Anxiety				
Anxiety	119	16.915±1.571	28.529±7.505	83.445±6.456
Mixed anxiety depression	38	16.210±1.378	29.894±7.842	82.578±8.002
p value		0.01	0.34	0.50
None				
None	55	9.891±3.275	18.182±3.221	91.691±4.207
p value		<0.0001	<0.0001	<0.0001
Age of the child				
3-7 years	110	17.273±3.065	32.573±10.630	76.8±14.355
>7 years	226	16.506±4.275	29.841±9.517	80.544±11.717
p value		0.09	0.02	0.01
Birth order of the child				
First child	268	17.071±3.886	31.776±10.075	78.437±13.131
Others	68	15.765±3.985	26.632±8.384	82.794±10.451
p value		0.02	0.0001	0.01
Gender of the child				
Male	206	16.709±3.943	30.786±10.160	80.40±11.874
Female	130	16.838±3.93	30.653±9.68	77.608±13.884
p value		0.8	0.9	0.05
Childs diagnosis				
ADHD	135	16.822±2.745	34.119±10.335	75.489±15.738
PDD	102	19.843±1.999	34.568±7.856	77.520±10.173
LD	99	13.495±4.215	22.172±4.947	86.394±5.960
p value		<0.0001	<0.0001	<0.0001
SES				
Low	27	17.926±2.074	41.741±9.79	61.592±14.962
Mid	185	16.876±4.207	32.146±9.728	77.135±11.002
High	124	16.331±3.771	26.234±7.597	86.432±9.304
p value		0.04	<0.0001	<0.0001
Neurological comorbidity in the child				
Present	200	18.075±2.389	33.180±9.044	76.415±12.772
Absent	136	14.824±4.859	27.140±10.190	83.588±11.470
p value		<0.0001	<0.0001	<0.0001
Psychiatry comorbidity in the child				
Present	151	18.993±2.401	36.007±8.428	72.828±13.616
Absent	185	14.935±4	26.432±9.021	84.616±9.037
p value		<0.0001	<0.0001	<0.0001
Type of family				
Nuclear	229	16.153±4.006	29.266±9.311	81.847±9.867
Joint	107	18.056±3.442	33.879±10.610	73.907±16.134
p value		<0.0001	<0.0001	<0.0001
Years since child illness				
< 1 year	94	16.798±3.191	30.553±9.819	80.681±11.011
>1 year < 5 years	194	16.824±4.286	31.392±10.027	78.046±13.678
>5 years -10 years	48	16.417±3.803	28.436±9.826	81.792±11.508
p value		0.55	0.07	0.08
Mothers education				
Up to 12 th grade	91	13.879±3.083	35.242±10.773	72.298±15.043
>12 th grade	245	16.343±4.137	29.061±9.114	81.927±10.688
p value		0.0014	<0.0001	<0.0001

DISCUSSION

This study is a part of a large study done in a quaternary care teaching institute in India on mothers of children with ADHD, PDD and LD. Even though the number of children diagnosed with ADHD, PDD and LD have increased in India, there is an abysmal disregard of the stress experienced by the caregivers of these children as evidenced by the lack of scientific reports or studies in Indian literature. This part of the study attempted to quantify stress related parameters in these mothers.

Perceived stress

Mothers in the ADHD and PDD group scored high in questions pertaining to “feeling nervous and stressed”, “inability to cope”, “feeling angered and irritable” and “difficulties piling up too high, that they were unable to overcome it” in the perceived stress scale. In a study done by Davis and Carter, parents of children with autism reported elevated parenting stress.²⁰ In this study too perceived stress was highest in mothers of children with PDD. Factors associated with high perceived stress in all three groups in this study included lower age of the child, being the first child, lower SES, presence of other comorbidities, being in a joint family and higher maternal education. Oelofsen and Richardson, described that parenting stress of children with developmental disability was high.²¹ They also noted a clear gender differences in dealing with parental stress. Few studies show that in mothers of children with ADHD, parenting stress, correlated highly with maternal psychopathology like depression and maternal depression could predict future conduct problems in children with ADHD.^{22,23} In this study too mothers with moderate depression scored highest in the perceived stress score.

Caregiver burden

The mothers in this study, rated questions regarding “having no privacy or time for themselves, feeling their health and social life has suffered”, with a high score because of caring for their affected child in the burden of care scale. They also reported “frequently” feeling stressed, strained, embarrassed and angry due to their care giving role. In a study done in the UK, comparing care giver burden of caring for a child with ADHD versus a child with autism, both disorders were associated with high levels of caregiver burden.²⁴ But caregiver burden was “significantly greater” in autism, with levels similar to that of caring for a person with a “brain injury”. “Unmet needs” like undiagnosed psychiatric comorbidity and inappropriate behavior were associated with greatest caregiver burden in both groups. In this study, BOC score was highest in the PDD group. In a large study done in 10 European nations by Fridman et al, on caregiver burden of children with ADHD, 75% of the caregivers were mothers and reported having to “miss work or change their schedule”, “plan their activities around the child” and “give up social activities”. The caregivers worried

about “people’s perception of them”. They also reported that caring for a child with ADHD, “put a tremendous strain on their family life”.²⁵ This study also showed similar findings as for parents of children with Down syndrome, as studied by Roach et al, mothers who reported more caregiving responsibility reported greater difficulties role restriction, and lesser spousal support on the contrary, fathers who took more responsibility for childcare perceived fewer difficulties with caregiving.²⁶ Ambikile and Outwater in a study in Tanzania, described caregivers of children with mental disorders had “feelings of sadness, and inner pain or bitterness” due to the behavioral problems of the child.²⁷ Apart from emotional problems they also experienced problems with communication, social stigma, lack of support and poor social life and economic challenges due to the increased expenditure arising from the child’s illness.

Quality of life

The mothers in the PDD and ADHD group of this study, scored low in questions dealing with “concentration, energy, sleep, anhedonia, anxiety and mood” in the quality of life scale. They also scored low in “relationship and personal satisfaction”. Khanna et al, in a study of health-related quality of life among primary caregivers of children with autism, found lower health related QOL scores than the general population.²⁸ Functional impairment in the child, lack of social support, and higher burden of care influenced caregiver mental health related QOL. In another study of QOL in parents of children with PDD, parents reported impairment in the following domains: physical activity, health and social relationships.²⁹ They also reported an overall “worse” perception of their QOL. The level of impairment were higher in mothers, especially in the physical and psychological domains. In a study of QOL in parents of children with ADHD done in Hong Kong, significantly lower scores in QOL was seen in the physical, psychological, social and environmental QOL domains.³⁰ In this study a significant higher QOL was seen in mothers with older children, higher birth order of the child, higher SES, absence of co-morbidity in the child, being in a nuclear family and higher maternal education.

Limitations of this study was no control group used. It was a single session study and no follow-up was possible as part of the study.

CONCLUSION

The current study has established increased stress levels parameters in mothers of children with common psychiatric problems. The study also establishes that these mothers had poorer quality of life. It is necessary to address these psychological issues of the mother at every visit and equip them with coping strategies so that they can look after both themselves and their special needs child.

Recommendations

- Primary caregivers of children with neuropsychiatric illness should be psycho educated about the nature of the child's condition at every visit as the child's needs and problems vary with every age.
- Caregivers should be screened for stress, anxiety and depression at every visit. Family members should be educated about the child's condition.
- Stress management techniques and coping skills should be proactively taught to the caregivers.
- Follow-up of child should include continued support to caregivers as well as a separate component.

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