

Burden and coping among caregivers of children with psychological disorders

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Abstract

Introduction: Children suffer from behavioural and mental illnesses like autism, hyperkinetic disorders, learning disorders, depression, anxiety disorders, conduct disorders, substance abuse, eating disorders and psychosis. These children are very difficult to manage for both the doctors and family care givers. The care givers are prone to burden and psychological disorders due to the impact of caring them. In India there are less studies regarding the caregiver's suffering. Hence this study was chosen to explore these parameters in detail.

Aim: To study the burden and coping among caregivers of children with psychological disorders. **Methodology**

and study tools: A cross sectional study on 70 caregivers of children and adolescents with different psychological disorders including mental retardation attending the Government hospital for Mental Care, Visakhapatnam. Children and adolescents with psychological disorders attributed to comorbid medical or neurological illnesses are excluded from the study. Burden assessment schedule and Brief Cope Scale were used in the study. The differences in the scores of each individual was compared with their sociodemographic factors as well. Data was collected using semi structured interview and results obtained were computed using appropriate statistical tests. **Results and Conclusion:** There is high degree of burden in the caregivers of children with maladaptive coping behaviours.

Keywords: caregiver, burden, coping, children, adolescents

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I. Introduction

Children suffer from mental and behavioural disorders like autism, hyperkinetic and learning disorders, depression, anxiety, conduct disorders, substance abuse, eating and other psychotic disorders. These children are very difficult to manage by both doctors and care givers. Such caregivers are more prone to develop burden and psychological disorders during the process of caring for them. Mental illness is defined as significant and persistent distress leading to impairment of functioning, with psychological or psycho-physical causes (Laylard & Clark)¹. Huang et al., in their study showed a high prevalence of psychological disorders in children. Every 1 in 5 children have a mental disorder that fulfils a diagnostic criteria and every 1 in 10 children have a severe mental disorder that results in significant socio functional impairment. Another important aspect is that many such affected children do not receive the right treatment for their illnesses. Nearly three fourths of children with psychological disorders never received any specialist psychiatric treatment². Caregivers of children particularly the parents face multiple difficulties during the process of care giving that includes stigma, self blame and marital discord. Family life of caregivers of such children had several limitations in various faculties in spending time with friends and neighbours, caring for other siblings, and participation in cultural and community events (Mendenhall and Mount)³. Child's abnormal behaviour was always considered as the single most important factor that contributed to caregiver's burden (Brannan & Heflinger)⁴. Parents of such children often experience feelings of guilt and self blame since many psychological disorders in children have biological basis (Moses)⁵. Approximately 3% of children have anxiety disorders, 1-2 % have ADHD and less than 1% have depressive disorder. Majority of children have conduct disorder (5%). Every 1 in 150 children have autistic spectrum disorder, but according to CDC (Center for Disease Control) this prevalence was much higher in US population accounting for 1 in 68 frequency⁶. In view of high degree of burden faced by caregivers or family members of children with psychological disorders, there is a great need for mental health professionals to aid in the process of giving care. Such an association will create an emotional outlet for the caregivers to reduce their suffering and improve the self belief and strengthen their mind (Mendenhall and Mount)³. The mental health professionals can administer semi structured scales or conduct qualitative interviews on these caregivers to

know the degree of burden and to identify those who require expert guidance. In India there are less studies regarding the caregiver's suffering. Hence this study was chosen to explore these parameters.

II. Review of literature

Burden of care has been defined as "the presence of problems, difficulties or adverse events which affect the life (lives) of the psychiatric patient's significant other(s)⁷. It is estimated that up to 20% of children and adolescents suffer from debilitating mental illness⁸. The care-giver is usually a relative of the ill person and the care given is invariably continuous. He or she often has added responsibilities in the family and many of the recipients do not recognise the help they are receiving. Previous studies have provided consistent evidence that the care givers of children with chronic mental disorders suffer from significant stress and moderately high levels of burden⁹. The care was given because of emotional bonding, duty, guilt and/or the lack of other available services in the community¹⁰. Parents of children with mental health disorders are more likely to cut work hours, to quit work, and to spend more time arranging for their child's care¹¹ and the time involved in caring for these children lead to lost opportunities¹². In addition to the emotional, psychological, physical and economic impact, the concept of 'burden of care' involves subtle but distressing notions such as shame, embarrassment, feelings of guilt and self-blame¹³. Angold et al¹⁴ reported that little attention has been paid to the parental burden resulting from caring for children and adolescents with psychiatric disorders, even in developed countries.

Child's Mental Health: Neuropsychiatric illness in children will continue to rise by more than 50 percentage by the end of the year 2020 causing greater degree of childhood disability according to World health organisation (WHO). According to CDC 2013 edition, psychological disorders can affect children of all regions, ethnicities and age, with males more likely to have greater incidence of disorders like ADHD (Attention deficit hyperactivity disorder), conduct disorders, ASD (Autism spectrum disorder) and tobacco use disorders. Females are more likely to suffer from depression and alcohol use disorders.

Caregiver's Experience: Caregiver is an adult living with or caring for a child who was diagnosed with a mental health illness. Experiences of the caregiver are very important in understanding the overall impact on the family. The better the management of the caregiver burden, the better will be the coping strategies of caregivers and finally greater well-being of the children with psychological disorders.

Burden: Brannan and Heflinger⁴ in their study showed that burden on caregivers arises from several aspects like guilt perception, sadness, disruption of family relationships, occupational interruption, financial distress etc. Indirectly the occupational and educational qualification also affects the caregiving services received by children. Burden can be additionally classified as subjective burden and objective burden. Objective burden was observed in the various aspects like finance, personal relationships, occupational discomfort etc. Subjective burden is the extent to which caregiver perceives the caregiver responsibilities (Liu, Lambert & Lambert)¹⁵.

Barriers or Hinderances: Owens et al., listed 3 major barriers that exist in delivery of mental health care to the affected children. They are structural and perceptual. Perceptual was again divided into those related to mental health disorders and those related to mental health services. Overcoming these barriers was the major role to be played by mental health specialists in order to deliver high quality of care and ease the burden in the caregivers to a significant degree¹⁶.

III. Aims and objectives

To study the degree of burden and coping among caregivers of children with psychological disorders.

Methodology and Study tools

A cross sectional study on 70 caregivers of children and adolescents (chosen by way of purposive random sampling) with different psychological disorders including mental retardation attending the outpatient department of Government hospital for Mental Care, Visakhapatnam, Andhra Pradesh during October to December 2017 were taken into study. Children and adolescents with psychological disorders attributed to underlying comorbid medical, surgical or neurological illnesses were excluded from the study. Likewise caregivers with comorbid medical, surgical or psychiatric disorders and those who didn't give a valid consent were also excluded from the study. Initially 100 caregivers were chosen for the study. Among them 9 didn't not give consent, 7 left the study midway, 6 had children with comorbid medical disorders, 8 caregivers had comorbid medical, surgical and psychiatric disorders (3 with Epilepsy, 3 with Bipolar affective disorder, 2 with COPD). After excluding these 30 participants, final sample size obtained was 70. **Burden assessment schedule (BAS) and Brief Cope Scale (BCS) were the tools used in the study.** The Burden Assessment Schedule is based on subjective and objective components of burden. It is composed of 40 items. It's a predominately a self

administered scale. Greater the score, greater is the degree of burden experienced by caregivers. Brief cope scale is a 28 item, self report questionnaire to assess a number of different coping behaviours and thoughts a person may have in response to a specific situation. Coping patterns were further subdivided into adaptive and maladaptive coping styles with scores ranging from 0-48 & 0-36 respectively. Each participant in the study was administered the relevant scales and the obtained results were analysed statistically.

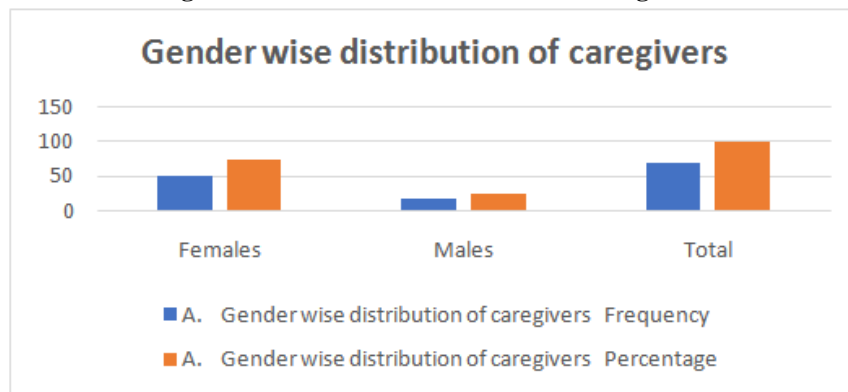
IV. Results

Data was analysed and results were obtained using SPSS package v25 and Microsoft Excel 2018.

Table 1: Gender wise distribution of caregivers

Gender	Frequency	Percentage
Females	52	74.3
Males	18	25.7
Total	70	100

Figure 1: Gender wise distribution of caregivers

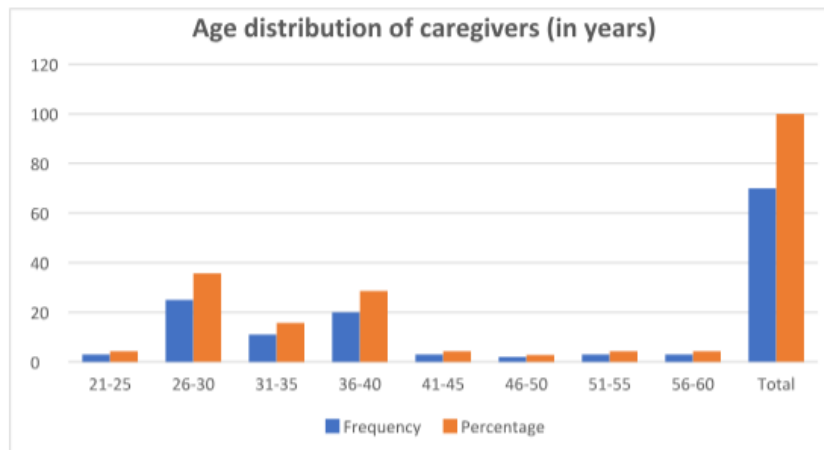


Majority of caregivers were females accounting for 74.3%.

Table 2: Age distribution of caregivers (in years)

Age group	Frequency	Percentage
21-25	3	4.3
26-30	25	35.7
31-35	11	15.7
36-40	20	28.6
41-45	3	4.3
46-50	2	2.8
51-55	3	4.3
56-60	3	4.3
Total	70	100

Figure 2: Age distribution of caregivers (in years)

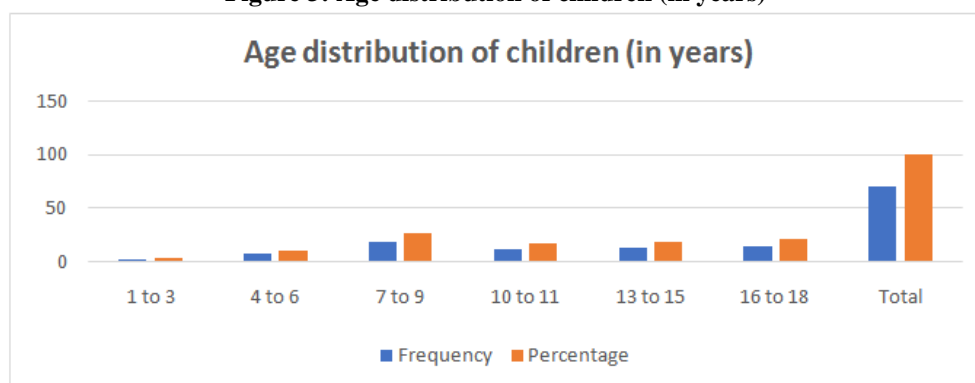


Majority of the caregivers belong to the age group 26 to 30 years followed by 36 to 40 years age group.

Table 3: Age distribution of children (in years)

Age group	Frequency	Percentage
1 to 3	3	4.3
4 to 6	8	11.4
7 to 9	19	27.2
10 to 11	12	17.1
13 to 15	13	18.5
16 to 18	15	21.5
Total	70	100

Figure 3: Age distribution of children (in years)

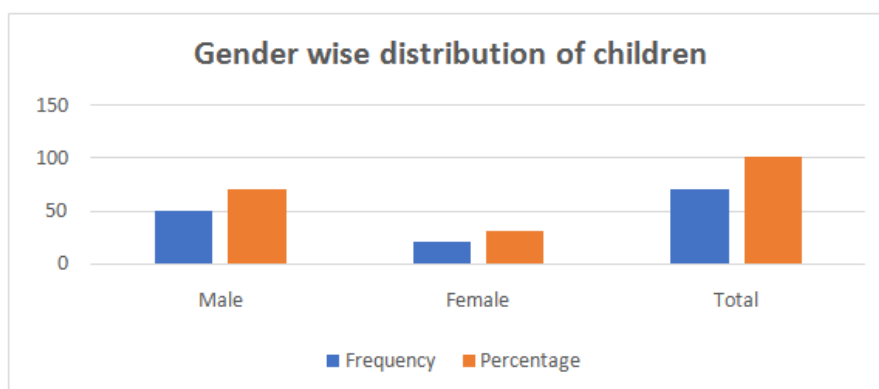


Majority of the children belong to age group 7 to 9 years (27%) followed by 16 to 18 years (21%).

Table 4: Gender wise distribution of children

Gender	Frequency	Percentage
Male	49	70
Female	21	30
Total	70	100

Figure 4: Gender wise distribution of children

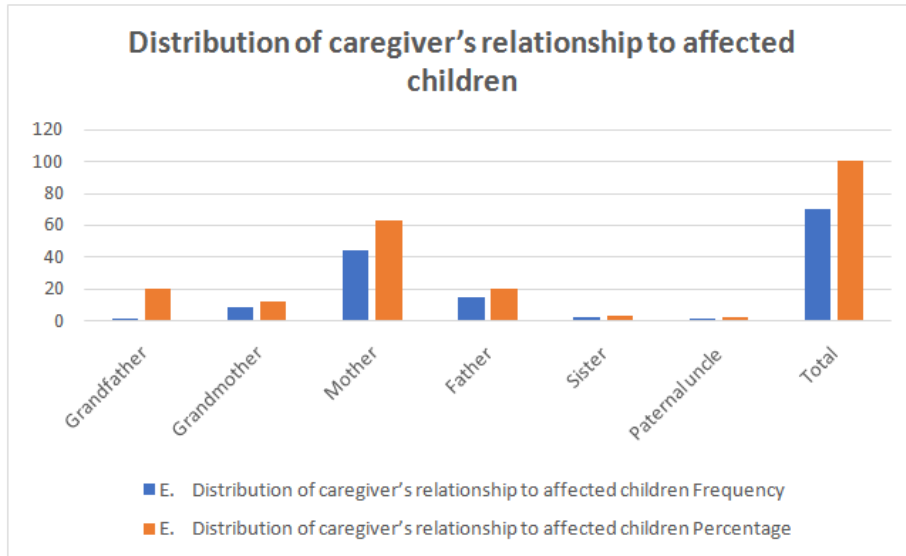


Majority of children were males accounting for 70%.

Table 5: Distribution of caregiver's relationship to affected children

Caregiver's relationship	Frequency	Percentage
Grandfather	1	20
Grandmother	8	11.5
Mother	44	62.9
Father	14	20
Sister	2	2.9
Paternal uncle	1	1.4
Total	70	100

Figure 5: Distribution of caregiver's relationship to affected children

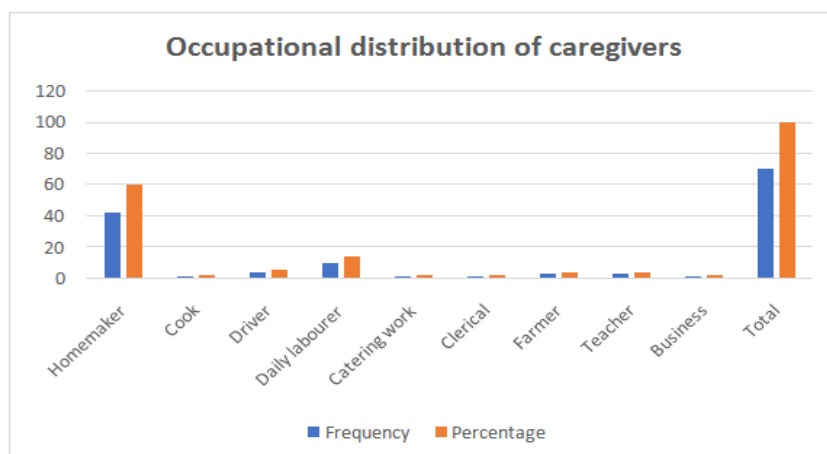


Majority of the caregivers were mothers (63%).

Table 6: Occupational distribution of caregivers

Occupation	Frequency	Percentage
Homemaker	42	60
Cook	2	2.8
Driver	4	5.8
Daily labourer	10	14.4
Catering work	2	2.8
Clerical	2	2.8
Farmer	3	4.3
Teacher	3	4.3
Business	2	2.8
Total	70	100

Figure 6: Occupational distribution of caregivers



Majority of the caregivers were mothers who were homemakers (60%).

Table 7: Marital status of the caregivers

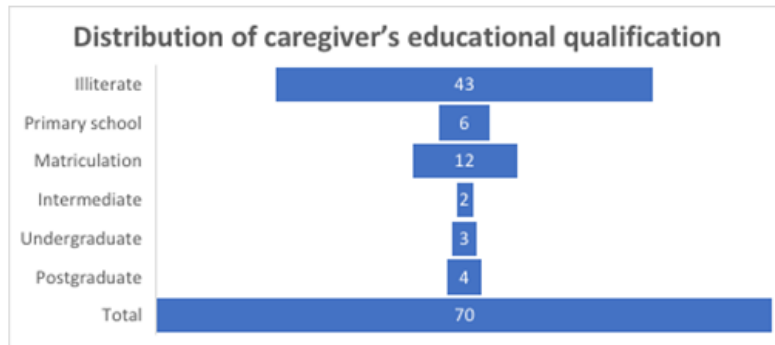
Marriage	Frequency	Percentage
Yes	69	98.6
No	1	1.4

Almost all the caregivers were married.

Table 8: Distribution of caregiver’s educational qualification

Education	Frequency	Percentage
Illiterate	43	61.4
Primary school	6	8.6
Matriculation	12	17.1
Intermediate	2	2.9
Undergraduate	3	4.3
Postgraduate	4	5.7
Total	70	100

Figure 8: Distribution of caregiver’s educational qualification

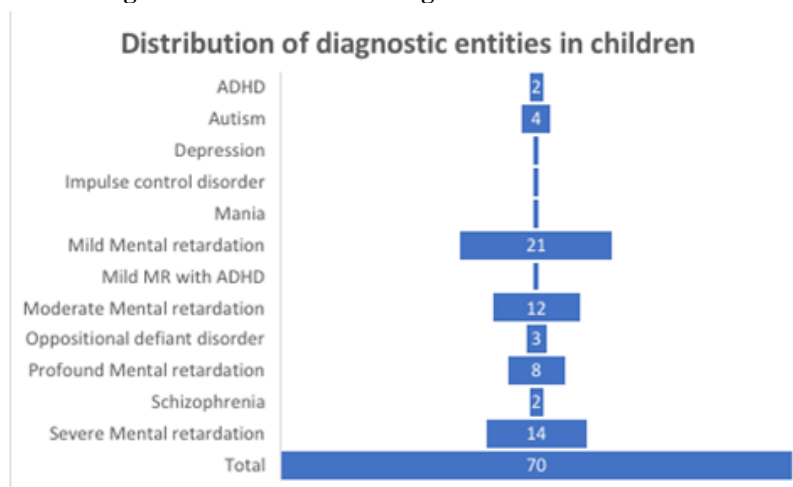


Majority of the sample was illiterate accounting for 61.5%

Table 9: Distribution of diagnostic entities in children

Diagnosis	Frequency	Percentage
ADHD	2	2.9
Autism	4	5.7
Depression	1	1.4
Impulse control disorder	1	1.4
Mania	1	1.4
Mild Mental retardation	21	30
Mild MR with ADHD	1	1.4
Moderate Mental retardation	12	17.1
Oppositional defiant disorder	3	4.3
Profound Mental retardation	8	11.4
Schizophrenia	2	2.9
Severe Mental retardation	14	20
Total	70	100

Figure 9: Distribution of diagnostic entities in children



Majority of the children of caregivers in the sample have mental retardation

Table 10: Distribution of scores of Burden Assessment Schedule(BAS) among the caregivers wrt their relationship with the child

Type of caregiver	Mean score BAS
Father	77.85
Mother	81.87
Grand father	67.00
Grand mother	81.61
Paternal uncle	77.00
Sister	81.00

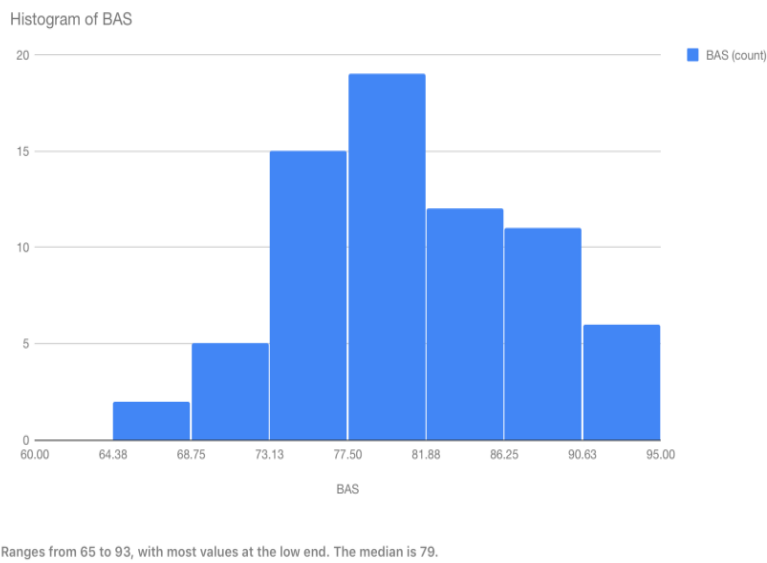


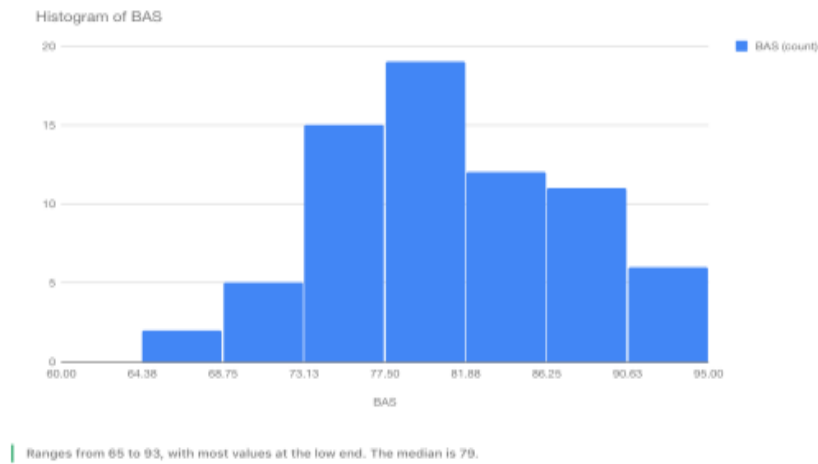
Figure 10: Distribution of scores of Burden Assessment Schedule(BAS) among the caregivers wrt their relationship with the child

Higher mean scores were obtained in the female caregivers (mother, grandmother and sister).

Table 11: Distribution of scores of Burden Assessment Schedule(BAS) among the caregivers wrt their educational qualification

Education of caregiver	Mean BAS
Post graduation	76.50
Illiteracy	84.51
Intermediate	81.00
Matriculation	78.16
Primary education	81.16
Under graduation	79.66

Figure 11: Distribution of scores of Burden Assessment Schedule(BAS) among the caregivers wrt their educational qualification

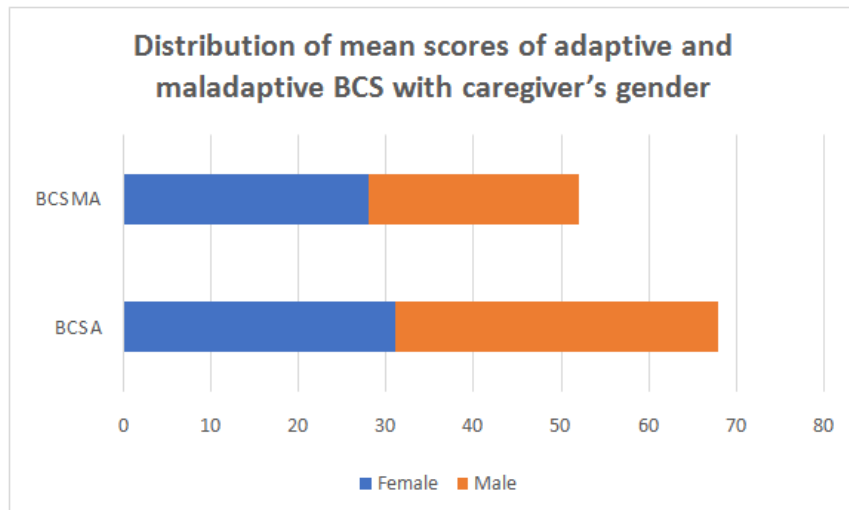


Higher scores are found in those caregivers who are illiterate and those with primary education.

Table 12: Distribution of Brief Cope scale scores (BCS)-Adaptive vs Maladaptive coping behaviours with gender

Gender	BCS (A) Mean	BCS (MA) Mean
Females	31	28
Males	37	24

Figure 12: Distribution of Brief Cope scale scores (BCS)-Adaptive vs Maladaptive coping behaviours with gender

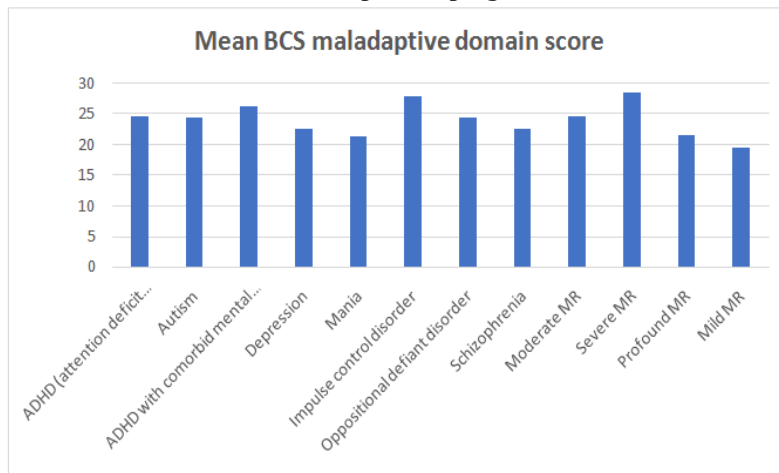


A= adaptive or favourable coping behaviours, MA= maladaptive or unfavourable coping behaviours. **Females have scored higher in the Maladaptive coping behaviours in comparison to males.**

Table 13: Distribution of mean scores of maladaptive coping behaviours with child’s diagnostic entity

Child’s diagnosis	Mean BCS maladaptive domain score
ADHD (attention deficit hyperactivity disorder)	24.50
Autism	24.3
ADHD with comorbid mental retardation (MR)	26.1
Depression	22.4
Mania	21.3
Impulse control disorder	27.7
Oppositional defiant disorder	24.3
Schizophrenia	22.5
Moderate MR	24.5
Severe MR	28.3
Profound MR	21.5
Mild MR	19.3

Figure 13: Distribution of mean scores of maladaptive coping behaviours with child’s diagnostic entity



Greater Maladaptive scores are obtained in Severe MR, Impulse control disorder and ADHD with comorbid mental retardation.

		BAS	BCS A	BCS MA
BAS	Pearson Correlation	1	-.392**	.429**
	Sig. (2-tailed)		.001	.000
	N	70	70	70
BCS A	Pearson Correlation	-.392**	1	-.386**
	Sig. (2-tailed)	.001		.001
	N	70	70	70
BCS MA	Pearson Correlation	.429**	-.386**	1
	Sig. (2-tailed)	.000	.001	
	N	70	70	70

**., Correlation is significant at the 0.01 level (2-tailed).

Table 14: Correlation statistics: BAS and BCS scores

Significant (at p 0.001) negative correlation is found between the scores of BAS (burden assessment) and maladaptive coping behaviours.

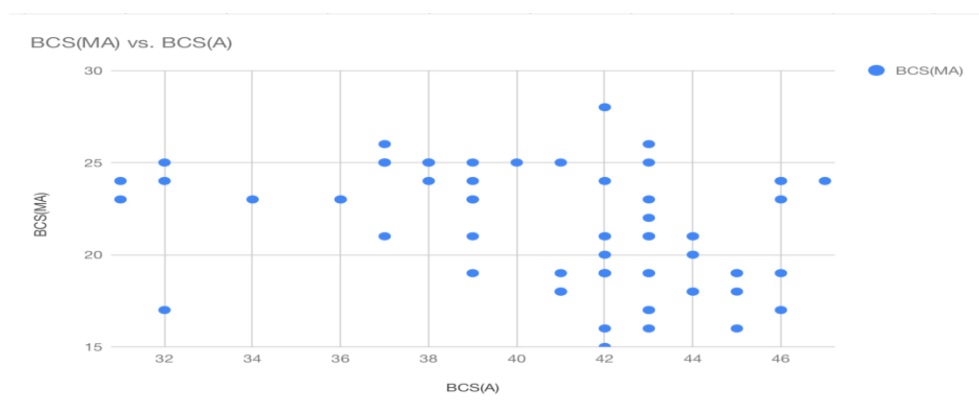


Figure 14: Correlation between mean scores of BAS (burden) and BCS (coping)

Negative correlation is seen between scores of BAS and BCS.

V. Discussion

This study showed a considerable degree of burden experienced by the caregivers of children with psychological disorders. The majority of caregivers in children with psychological disorders were women (74.3%) and their mothers constituted approximately 84.6% of them. Significant difference is also found between the caregivers of two genders with females scoring high on burden scores. This could probably be related to greater involvement of women in household works in addition to looking after their children. Many of the caregivers experienced feelings of guilt, self blame, and grief during the process of giving care to their children. Few women reported conflicts with their life partners and friends as they did not have enough time to care for their needs. These findings are supported by the study carried by Richardson et al, where parents expressed shock, sadness and self blame in offering care to their psychologically disabled children¹⁷. Many of the caregivers also reported deficiencies in adequate care offered by mental health care agencies and reported shortage in services to deal with such children in an expert way. Many of the caregivers also reported significant stigma they faced in rearing their children with such disabilities. Thus they are subjected to more burden.

Significant negative correlation is found between the caregiver's burden and the ways of coping. Caregivers experiencing greater burden are more likely to resort to the usage of unhealthy coping behaviours like denial, behavioural disengagement, substance use and self blame. Positive coping strategies mainly focused on attaining strength from spiritual and religious guidance. There is greater use of maladaptive coping than adaptive behaviour in the due course of time. In our current study the care givers have adopted both adaptive and maladaptive coping behaviours. Greater maladaptive coping is found in female gender when compared with males. The median age of caregiver is 32.5 yr. Likewise significant maladaptive coping is found in caregivers of children with clinical diagnostic entities like severe mental retardation, impulse control disorders when compared with other diagnostic entities. Similar results were obtained in the studies conducted by LiuM et al., in China¹⁵ and in one Nigerian cross sectional study¹⁸.

Limitations of the study: Sample is drawn from a cross section of population attending a tertiary care hospital. Thus results cannot be applied to the community as a whole. Personality structure of the caregivers is not considered in the study.

VI. Conclusion

There is high level of burden and coping difficulty among caregivers of children with psychological disorders. Increased burden leading to a maladjusted life style and difficult coping which in return affects the care to the child with psychological disorders. There is high need to address the barriers faced by the caregivers in order to improve overall well-being of the child and the caregiver.

Issues of conflict: None

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