



Assessment of caregiver burden among attendants of psychotic & neurotic patients: A comparative study

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Abstract

Background: Almost 80% caregivers experience burden. There are two types of caregiver burden- Objective and Subjective. Chronicity, symptom severity, relapses/exacerbation of psychiatric illness needing hospitalization affect family dynamics and routine, finances, quality of life, emotional expression, interpersonal/social relationships of both patient and family. Analyzing caregiver burden can provide data for decision-making, generation of intervention strategies for holistic care, efficient care-giving and appropriate intervention. **Aim: To compare caregiver burden among neurotic and psychotic patients. Settings and Design:** This was a longitudinal hospital-based study conducted over one year. A total of 100 subjects, 50 each of neurotic (F40-F48) and psychotic (F20-F29) illnesses as per ICD-10 fulfilling the inclusion and exclusion criteria were enrolled using consecutive sampling. Psychiatric interview of the subject was conducted using structured proforma. Diagnostic confirmation and severity assessment was done as per ICD-10 guidelines and appropriate scales (BPRS, HAM-D and Y-BOCS). The caregivers' burden was assessed using Family Burden Interview Schedule (FBIS). Follow-up was done at one, three and six months. **Results:** Maximum caregivers were parents followed by spouses. In neurotic group, maximum caregivers were from upper middle while those of psychotic group belonged to upper lower socio-economic status ($p=0.005$). Psychotic patients had significantly longer duration of illnesses ($p=0.000$), early onset of disease ($p=0.011$). Caregivers of psychotic group had more total and objective mean burden scores, individual domains compared to caregivers of neurotic group at baseline and follow-ups. A positive correlation was found between disease severity among most of patients and caregiver burden on FBIS at baseline and follow-ups except patients with OCD who had significant positive correlation at six months only. **Conclusion:** Caregivers of psychotic patients suffered a higher total and domain-wise burden than caregivers of neurotic patients. This may be attributed to earlier onset and a higher duration of illness in psychotic patients.

Key words: Caregiver, burden, psychotic, neurotic

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Background

Studies show that almost 80% of caregivers experience burden in their duties [1]. There are two types of caregiver burden- Objective and Subjective; Objective burden refers to quantifiable challenges faced by caregivers such as physical burden of care while subjective burden is caregiver's personal appraisal of situation and the extent to which he/she perceives the burden [2]. The chronic nature of psychiatric illnesses, its symptom severity, and the occurrence of multiple relapses/exacerbation of symptoms leading to hospital admissions causes significant changes in family dynamics and routine, expression of emotions, finances, quality of life, and interpersonal or social relationships of both patient and family members [3]. Due to inadequate community-based support system in developing countries, care-giving of patients depends entirely upon their family members which lead to higher levels of burden upon them [4]. Analysis of caregiver burden can provide required data for decision-making, generation of intervention strategies for holistic care. For effective and positive care-giving, early assessment and intervention for caregiver burden like counselling, psycho-education and family intervention is necessary [1]. Hence this study is conducted which compares caregiver burden among neurotic and psychotic patient's caregivers over three follow-up periods.

Materials and methods

Study setting and design:

This study was a comparative longitudinal hospital-based study conducted in a tertiary care hospital in Punjab over one year. Data collection was done in May-Jun 2020 to May-Jun 2021. Subjects aged between 18 and 65 years, registering as OPD/IPD patients, fulfilling the inclusion and exclusion criteria for the study were

enrolled.

Inclusion and exclusion criteria:

Patients meeting ICD-10 criteria for diagnosis of Psychotic disorders (F20-F29 as per ICD-10) and Neurotic, Stress-related and Somatoform disorders (F40-F48 as per ICD-10) were enrolled. Patients having neurological illness, organic brain syndrome, medical illness, intellectual disability and head injury were excluded.

Primary caregiver aged 18-65 year who have been staying with patient for a minimum of six months, taking care of daily needs of patient, supervising medication and coordinating with treating team were enrolled. While caregivers having any psychiatric illness, neurological illness, organic brain syndrome, medical ailment, intellectual disability and head injury were excluded.

Sample size and technique:

A recent study using FBIS [5] found that 85.3% caregivers of schizophrenia patients reported moderate to severe burden. Calculating sample size using this data:-
 $N = z^2 pq / d^2$; taking absolute error as 10%,
 $N = 1.96^2 \times 0.853 \times 0.147 / 0.1^2$
 $N = 48.17$

Hence a total of 50 psychotic patients were included. For comparison, an equal number of neurotic patients were taken, making a total of 100 subjects. Sampling was done using a non-probability consecutive sampling technique.

Study procedure:

Psychiatric interview of the subject was conducted with the help of pre-validated structured Psychiatric evaluation Performa. Subject's chief complaints, history of illness and symptoms' severity were assessed using appropriate scales. Appropriate scales for diagnostic confirmation and severity assessment were applied- Brief psychiatric rating scale (BPRS) [6], Hamilton Depression Rating Scale (HAM-D) [7] and Yale-Brown Obsessive Compulsive Scale (Y-

BOCS)[8]. A total 100 patients were recruited in the study with 50 patients each of neurotic (F40-F48 as per ICD-10) and psychotic illness (F20-F29 as per ICD-10). The patients' caregivers were then subjected to Family Burden Interview Schedule (FBIS)[9]. It measures both objective burden and subjective burden on the family members. The baseline score was recorded and then follow ups were taken up at the end of one month, three months and six months to re-assess burden using FBIS.

Instruments:

1. Psychiatric evaluation proform

a: Psychiatric Interview Proform devised by the Department of Psychiatry of the institution was applied to find out the history, duration and course of illness of subjects.

2. Family Burden Interview Schedule

(FBIS): A validated scale which measures both objective burden and subjective burden in family. It has 24 items grouped under 6 areas of burden, namely 1) financial burden, 2) disruption of routine family activities, 3) disruption of family leisure, 4) disruption of family interactions, 5) effect on physical health of others and 6) effect on mental health of others. Each item is rated on a 3 point scale- zero indicating no burden, one indicating moderate and two indicating severe burden. It also assesses subjective burden. Score on the objective burden is the total score which ranges from 0-48; 0 score means no burden, 1-24 means moderate burden and 25-48 means severe burden [9].

Ethics:

Approval for the study was sought from Institutional Ethics Committee. Written Informed consent was taken from patients and caregivers before enrolment. Data was kept strictly confidential.

Statistical analysis:

The data pertaining to socio-demographic and other clinical variables was

analyzed using IBM SPSS version 20. Data were described in terms of range; mean \pm standard deviation (SD), frequencies (number of cases) and relative frequencies (percentages) as appropriate. Comparison of quantitative variables between the study groups was done using Student t-test and for within the variables was done using paired t-test. For comparing categorical data, Chi square (χ^2) test was performed and exact test was used when the expected frequency is less than 5. Pearson's 'r' was used for correlation analysis. A probability value (p value) less than 0.05 was considered statistically significant.

Results

A total of 50 consecutive patients each of neurotic (F40-F48 as per ICD 10) and psychotic illnesses (F20-F29 as per ICD 10) who fulfilled the inclusion/ exclusion criteria were included in the final analysis.

On socio-demographic comparison among both neurotic and psychotic groups (Table 1), maximum caregivers in both groups were parents, with more spouses as caregiver in neurotic and more siblings in psychotic patients ($p=0.046$). In neurotic group maximum

caregivers were from upper middle socio-economic status while most caregivers of psychotic group patients belonged to upper lower status ($p=0.005$). Based on mean score variables (Table 2), psychotic patients had significantly longer duration and early onset of illness as compared to neurotic patients ($p<0.001$ and 0.011 respectively).

Comparison of caregiver burden based on FBIS scale (Table 3) shows that caregivers of psychotic group had more total and objective mean burden scores as compared to caregivers of neurotic group at baseline and follow-ups. Similar results were obtained when individual domains of family burden interview schedule were compared at baseline and follow-ups; the differences being

highly significant for all comparisons ($p < 0.01$). On correlation analysis (Table 4), a positive correlation was found between disease severity among most neurotic and psychotic patients with caregiver burden on FBIS at baseline as well as follow-ups ($p < 0.001$) except patients with OCD who had significant positive correlation at six months only ($p = 0.008$).

Discussion

Socio-demographics and illness variables:

a. Patients

Considering age of patients, maximum neurotic patients 22 (44%) belonged to 18-25 years. In group 2 (psychotic), 21 (42%) patients were from 18-25 and 25-35 age groups each. Similarly in a study conducted by Chadda et al [10] it was found that, 44% of the patients with bipolar affective disorder were in the age group 15-30 compared to 36% in the schizophrenia group. In neurotic group there were 20 (40%) males and 30 (60%) females. In group psychotic there were 29 (58%) males and 21 (42%) females. The results were similar to study conducted by Behere et al [11] in which majority Schizophrenic patients were males (56%) compared to Depression, with more females (67%). Regarding family type, in our study the overall trend was of nuclear 46% > joint family 38%. Similar results were found in study conducted by Behere et al [11] in which overall trend was of nuclear (84%) > joint families (16%). In present study 52% patients belonged to urban locality and 48% rural locality. These findings were similar to study conducted by Ayalew et al [12] in which 50% patients each were residing in urban and rural locality. Mean duration of illness in neurotic patients of this study was 1.7 ± 2.5 years and 5.2 ± 5.2 years in psychotic group. Oza et al [13] found mean duration illness in OCD (neurotic) group was 8.7 ± 6.6 years and in schizophrenia (psychotic) group was 8.8 ± 5.1 years.

b. Caregivers

In our study, in both groups maximum caregivers were parents (57%) followed by spouses (33%). However, relatively more spouses were caregivers in the neurotic group 22 (44%) than psychotic group 11 (22%). Further, maximum psychotic patients were single which explains more number of parents as caregivers in psychotic group. When the relationship of primary caregiver with patient was studied, Behere et al [11] found that mostly parents were primary caregiver in case of Schizophrenia (39%) and in case of Depression, caregivers were mostly spouses (60%). Overall in our study 55% caregivers were from 25-45 age group. These findings were similar to study conducted by Walke et al [14] with majority caregivers in age group of 31-50 years (55.6%).

The overall pattern of socio-demographic characteristics was hence found similar to previous research, considering many Indian studies have been conducted, albeit on singular disorders rather than all neurotic and psychotic disorders.

Comparison of caregiver burden:

Based on FBIS, caregiver burden was higher in caregivers of psychotic patients as compared to neurotic group in all domains (financial burden, disruption of routine family activities, disruption of family leisure, disruption of family interactions, and effect on physical and mental health of others). More burden in caregivers of psychotic group may be due to earlier onset and higher duration of illness. Other factors may include need for continuous and long-term treatment, requirement of more assistance in routine activities, poor insight, or the active symptomatology causing socially inappropriate behaviour.

Similar results were also found in study conducted by Oza et al [13] in which the burden of care was higher in the schizophrenia in all domains except "effect on mental health", where burden was slightly higher in the OCD group. The

difference was statistically significant for the domain of "disruption of routine family activities", which was higher in caregivers of schizophrenia ($p=0.038$). Similar findings were also noted by Gururaj et al [15] among the six dimensions of the family burden schedule, with schizophrenia (psychotic) patients having higher scores on financial burden (5.6 ± 3.7 vs. 8.61 ± 4.9 , $p=0.006$) and disruption of routine family activities (6.8 ± 2.7 vs. 8.7 ± 2.4 , $p=0.012$). Family burden was significantly higher in schizophrenia patients compared to those with OCD (neurotic) (28.6 ± 10.4 versus 37.8 ± 11.2 , $p=0.004$).

Correlation of illness severity and caregiver burden:

Correlation analysis of neurotic illnesses showed that increase in HDRS severity lead to an increase in burden scores at baseline and follow-ups. Comparing YBOCS scores in OCD; an increase in YBOCS score at six month follow-up was significantly correlated (high positive correlation; $r>0.7$) with burden scores. Previous research by Suculluoglu-Dikici et al [16] showed similar results- YBOCS obsession ($r=0.47$), compulsion ($r=0.47$), and total scores ($r=0.52$); HAM-D scores ($r=0.32$) positively correlated with disease burden ($p<0.05$).

Correlation analysis between BPRS and burden scores at baseline and follow-ups showed that at each follow-up, an increase in BPRS scores, i.e. severity was associated with an increase in burden. Similar results were found in study conducted by Okafor et al [17] in which there was positive association between the patients score on BPRS and subjective/objective burden.

Strengths, limitations and future direction

Rigorous inclusion criteria were set beforehand to reduce selection bias, clear definition for primary caregiver was used. Confirmation of diagnosis was done by Psychiatrist In-charge of department to address interviewer bias. Due to a hospital-based design, generalizability of the study

results is limited. Further, consecutive sampling may have induced inadvertent bias. Future studies should be done in a larger representative sample for better results. Direct comparison wasn't made with mood disorders (F30-F39), which require further research.

Conclusion:

Caregivers of psychotic patients suffered a higher total and domain-wise burden than caregivers of neurotic patients. This may be attributed to earlier onset and a higher duration of illness in psychotic patients.

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Tables/Figures

Table 1: Socio-demographic comparison

Parameter(s)	Categories	Patients			p value*	Caregivers			p value*
		Total N=10	Neurotic	Psychotic		Total N=10	Neurotic	Psychotic	
		n/%	n (%)	n (%)		n/%	n (%)	n (%)	
Age (years)	18-25	43	22	21	0.606	2	0	2 (4)	0.560
	25-35	37	16	21		28	14	14	
	35-45	14	9 (18)	5 (10)		27	14	13	
	45-60	6	3 (6)	3 (6)		43	22	21	
Gender	Male	49	20	29	0.072	78	42	36	0.148
	Female	51	30	21		22	8 (16)	14	
Education	Professional	9	6 (12)	3 (6)	0.652	2	1 (2)	1 (2)	0.763
	Graduate	22	10	12		24	10	8 (16)	
	Intermediate	26	13	13		16	8 (16)	11	
	High school	21	11	10		29	2 (4)	1 (2)	
	Middle school	6	2 (4)	4 (8)		3	1 (2)	1 (2)	
	Primary school	9	3 (6)	6 (12)		2	10	14	
	Illiterate	7	5 (10)	2 (4)		24	10	14	
Caregiver occupation	Professional	N/A			-	12	7 (14)	5 (10)	0.185
	Clerk					7	2 (4)	5 (10)	
	Skilled worker					12	6 (12)	6 (12)	
	Agriculture					37	24	13	
	Machine					12	5 (10)	7 (14)	
	Elementary					1	0	1 (2)	
	Unemployed					19	6 (12)	13	
Religion	Hindu	31	14	17	0.466	N/A			-
	Sikh	68	36	32					
	Christian	1	0	1 (2)					
Family type	Nuclear	46	23	23	1.000	N/A			-
	3-gen	16	8 (16)	8 (16)					
	Joint	38	19	19					
Marital status	Single	50	22	28	0.123	6	2 (4)	4 (8)	0.469
	Married	42	26	16		88	46	42	
	Divorced	6	1 (2)	5 (10)		0	0	0	
	Widow	2	1 (2)	1 (2)		6	2 (4)	4 (8)	
Locality	Rural	48	29	19	0.071	N/A			-
	Urban	52	21	31					
Relation with patient	Parents	N/A			-	57	26	31	0.046
	Siblings					7	1 (2)	6 (12)	
	Spouse					33	22	11	
	Children					3	1 (2)	2 (4)	

Variables common to patients and caregivers					
Family income	≥123322	4	4 (8)	0	0.00 0
	61663-123321	16	16 (32)	0	
	46129-61662	22	13 (26)	9 (18)	
	30831-46128	17	5 (10)	12 (24)	
	18497-30830	39	12 (24)	27 (54)	
	6175-18496	2	0	2 (4)	
Socio-economic status	Upper	1	1 (2)	0	0.00 5
	Upper Middle	39	27 (54)	12 (24)	
	Lower Middle	31	14 (28)	17 (34)	
	Upper Lower	29	8 (16)	21 (42)	
Family psychiatric	Negative	71	33 (66)	38 (76)	0.27 1
	Positive	29	17 (34)	12 (24)	

* Chi-square test used

Table 2: Comparison of mean score variables

Parameter	Neurotic; n=50	Psychotic; n=50	t value	p value*
Patients' Age	29.4 ± 8.8	28.8 ± 8.8	0.339	0.735
Caregivers' Age	43.2 ± 9.4	43.4 ± 10.6	-0.129	0.897
Distance from hospital (km)	37.3 ± 25.7	42.9 ± 25.4	-1.087	0.280
Duration of illness (DOI) in years	1.7 ± 2.5	5.2 ± 5.2	-4.339	0.000
Age of onset (AoO) in years	27.9 ± 8.6	23.6 ± 7.9	2.602	0.011

*Independent 't' test used.

Table3: Comparison of Family Burden (FBIS)

Parameter (Mean ± SD; p value)	Baseline		1 month		3 months		6 months	
	Neurotic	Psychotic	Neurotic	Psychotic	Neurotic	Psychotic	Neurotic	Psychotic
Total burden (FBIS)	12.7±10.2	29.1±9.8	17.2±9.8	30.1±7.9	15.8±9.3	27.8±8.1	12.1±9.9	23.4±10.4
	0.000		0.000		0.000		0.000	
Objective burden	11.6±9.6	27.3±9.5	15.9±9.2	28.2±7.8	14.5±8.8	26.0±7.9	11.0±9.3	21.8±10.0
	0.000		0.000		0.000		0.000	
FBIS Domains								
Financial burden	3.1±3.0	6.2±3.1	4.7±2.7	6.4±2.1	4.8±2.6	6.1±2.2	3.9±2.9	5.5±2.9
	0.000		0.001		0.009		0.005	
Disruption of routine family activities	3.7±3.0	7.3±2.6	4.8±3.0	7.7±2.1	4.1±2.9	6.8±2.0	3.1±3.0	5.9±2.2
	0.000		0.000		0.000		0.000	

Disruption of family leisure	1.4±2.0	3.5±2.6	2.4±2.0	3.5±2.1	2.1±1.8	3.2±1.9	1.3±1.7	2.3±1.9
	0.000		0.009		0.005		0.013	
Disruption of family interactions	2.8±2.7	8.0±2.6	3.1±2.5	7.8±2.5	2.5±2.2	7.1±2.3	1.9±2.1	5.7±2.5
	0.000		0.000		0.000		0.000	
Effect on physical health of others	0.2±0.7	0.8±1.1	0.2±0.7	0.7±0.9	0.2±0.6	0.7±0.8	0.1±0.4	0.6±0.9
	0.001		0.002		0.001		0.001	
Effect on mental health of others	0.4±0.8	1.5±1.3	0.8±1.0	2.0±1.0	0.9±1.0	2.1±0.8	0.8±1.0	1.9±1.2
	0.000		0.000		0.000		0.000	

*Independent 't' test used.

Table 4: Correlation analysis of variables

Parameter*	Categories	HDRS n=38	YBOCS n=12	BPRS n=50
		Severity scores at Baseline		
Burden total at baseline	Pearson's 'r'	0.643	-0.253	0.483
	p value	0.000	0.427	0.000
		Severity scores at 1st follow-up		
Burden total at 1 month	Pearson's 'r'	0.585	0.221	0.513
	p value	0.000	0.491	0.000
		Severity scores at 2nd follow-up		
Burden total at 3 months	Pearson's 'r'	0.629	0.520	0.707
	p value	0.000	0.083	0.000
		Severity scores at 3rd follow-up		
Burden total at 6 months	Pearson's 'r'	0.860	0.721	0.830
	p value	0.000	0.008	0.000

*Pearson's correlation