Cloud Publications
International Journal of Advanced Nursing Science and Practice
2012, Volume 1, Issue 1, pp. 20-28, Article ID Med-18
ISSN 2320 - 0278

Research Article **Open Access**

Burden among Caregivers of Clients with Depression – A Scientific Study

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Publication Date: 19 November 2012

Article Link: http://medical.cloud-journals.com/index.php/IJANSP/article/view/Med-18

Abstract Burden among 30 caregivers of in-patients with depression was assessed using the BASS (Burden assessment scale, Thara etal., 1995). **:** Data obtained was analysed using spss 16 with descriptive statistics, t test & pearsons correlation coefficient. The subjective burden levels ranged from 67-98 and Mean Burden was 84.7 ± 9.7 suggesting moderate burden perception by the caregivers. Individual domain standardized percentage scores indicated highest burden in the domain of physical & mental health (67.9), taking responsibility (67.5), patients' behaviour (63.8), and caregivers' routine (61.3). Indian families are very close knit and perhaps hence standardized percentage scores seemed to be comparatively less in the other domains such as support of patient (53.8), caregivers strategy (51.3), other relations (50.0), spouse related (46.3) and external support (35.8). Mean Burden level in female caregivers (17.3) was significantly ($p<0.05$) higher than in male caregivers (15.5). High burden levels could predispose to depression, substance abuse, anxiety, etc. in caregivers of patients with depression. This study results indicate the need for family based interventions addressing this issue.

Keywords *Burden, Caregiver, Depression*

1 Introduction

The global burden of mental disorder is increasing. Depression alone is reported to be one of the leading causes of disability worldwide, accounting for 4.4% of lost years of healthy life due to premature death or disability (DALYs) on a global basis. Researchers generally agree that mental disorder represents a burden to the caregiver and family [1]. Depression affects persons activities of daily living (basic and/or instrumental), occupational abilities, psycho-social functioning and sexual life. Quality of life is affected to a great degree. Over the past few decades, due to de-institutionalization, revolving door syndrome and community based rehabilitation, the onus of caring falls on the caregiver contributing to increased patient contact hours. The strain of caring for these persons impacts caregivers to a great extent.

2. Methodology

A descriptive cross-sectional research design was adopted to assess the level of subjective burden in 30 caregivers of in-patients with depression recruited using convenience sampling technique in a specific tertiary care neuro-psychiatric hospital at Bangalore.

Caregivers of both gender in-patients with depression were included in the study while caregivers with sensory deficits were excluded. Interview rooms in the psychiatric wards were used to collect data from the subjects using the BAS (Burden Assessment Schedule, Tara etal., 1995 and the socio-demographic profile). The BASS was developed & standardized by step wise ethnographic exploration method. The inter rater reliability is high (Kappa: 0.80). Has high content validity. Criterion validity was established by comparing with the Family Burden Schedule (Pai & Kapur, 1981) – values ranged between 0.71-0.82. There are 40 items rated on a three point scale (1-3). 1- Mild burden, 2-moderate burden & 3-severe burden. A score of 40 on the BASS would indicate no burden, 80 moderate burdens and 120 extreme burdens. There are 9 domains. Increasing scores indicate increasing levels of burden. This scale has been used many times in the Indian setting. Ethical issues such as confidentiality and anonymity were ensured and assured. Data obtained was analysed using spss 16 with descriptive statistics, t test and pearsons correlation coefficient.

Research on caregiver burden has traditionally focused on relatives of individuals with severe mental disorders like schizophrenia [2, 3, 4], bipolar disorder [5, 6], and dementia [7]. Although more disorders have been included in recent research [8], there are few studies on families of individuals suffering from anxiety and depression disorders, and it has been pointed out that there is a lack of research based on large sample sizes and control groups [6, 9, 10, 11].

Caregiver burden refers to the significant amount of strain and difficulties experienced by the caregiver or family of mentally ill people, including a range of psychological, emotional, social, physical and financial problems [12, 13, 14, 15, 16]. Studies reporting that the burden of depression is smaller or more infrequent compared to the burden of for example bipolar disorder [17], schizophrenia [10] or dementia [18] may lead to a general perception that burden is larger for the more severe psychiatric diagnoses; however, other studies comparing the burden of depression with the burden of schizophrenia [11] or dementia [19] found similar amounts of burden. Furthermore, a study of partners of people suffering from anxiety disorders, depression or schizophrenia did not find any support for a relationship between strength of burden and type of diagnosis or duration of the illness, but rather between burden and level of impairment in everyday functioning [20]. Idstad, Ask & Tambs (2010) observed that the spouses of persons with depression reported higher levels of symptoms of anxiety and depression and lower levels of subjective well-being compared to the other population. This observation may support earlier studies which found that spouses of depressed individuals are at risk of developing depression themselves [10, 20, 21, 22, 23, 24, 25]. These contradictory reports aroused interest and curiosity in the researchers which formed the base for this study.

3. Results

Table 1: *Frequency distribution of the caregivers based on socio-demographic variables (n=30)*

Variable	No. (n = 30)	Percentage
Gender		
Female	17	56.7
Male	13	43.3
Religion		
Hindu	24	80.0
Christian	3	10.0
Muslim	3	10.0
Marital status		
Single	6	20.0
Married	24	80.0
Education		
Nil	3	10.0
High school	15	50.0
UG	9	30.0
PG	3	10.0
Occupation		
Nil	3	10.1
Student	1	3.3
Housewife	10	33.3
Unskilled	0	0
Semi-skilled	7	23.3
Skilled	9	30.0

Table 2: *Frequency distribution of the study sample based on age (n = 30)*

Variable	Range	Mean ± SD
Age of Caregivers	16-67	42.9 ± 15.5
Age of patients	11-76	36.7 ± 16.3

Table 3: *Frequency distribution of the patients based on socio-demographic variables*

Sample Characteristics	f(n = 30)	Percentage
Ward		
Closed wards	2	6.7
Open wards	22	73.3
Child psychiatric wards	3	10.0
ICU	3	10.0
Marital Status		
Single	11	36.7
Married	18	60.0
Divorced	1	3.3
Gender		
Male	19	63.3
Female	11	36.7
Income		
< 1700 (Non-paying)	10	33.3
1700-5000	11	36.7
>5000	9	30.0

Table 4: *Frequency distribution of the patients based on Illness Profile (n = 30)*

Variables	F	Percentage
Diagnosis		
Severe Depression	15	50.0
Moderate Depression	6	20.0
RDD	9	30.0
Episode		
First	9	30.0
Second	10	33.3
Multiple	11	36.7
Number of hospitalizations		
First	10	33.3
Second	12	40.0
More than 2	8	26.7
Caregivers perception of reason for relapse		
Poor treatment response	10	33.3
Non-compliance	5	16.7
Stress	15	50.0

Table 5: *Level of Burden in Caregivers (Domain wise) (n=30)*

BASS Domains	Range (BASS)	Range (Subjects)	Mean ± SD	Mean percentile
Spouse related	4-12	4-11	7.7 ± 2.1	46.3
Physical & Mental Health	7-21	11-20	16.5 ± 2.1	67.9
External Support	6-18	6-17	10.3 ± 2.3	35.8
Caregiver routine	4-12	6-12	8.9 ± 1.6	61.3
Support of Patient	4-12	5-11	8.3 ± 1.4	53.8
Taking responsibility	4-12	7-11	9.4 ± 1.2	67.5
Taking responsibility	4-12	7-11	9.4 ± 1.2	67.5
Other relations	3-9	3-9	6.0 ± 1.8	50.0
Patient’s Behaviour	4-12	6-12	9.1 ± 1.6	63.8
Caregiver strategy	4-12	4-11	8.1 ± 1.4	51.3
Total Burden Score	40-120	67-98	84.7 ± 9.6	55.8

Table 6: *Gender wise Comparison of Level of Burden in Caregivers (n=30, *p<0.05)*

BASS Domains	Mean ± SD	t	p value
Spouse related			
Male (n=12)	7.9 ± 1.7	0.454	.654
Female (n=15)	7.5 ± 2.5		
Physical & Mental Health			
Male (n=13)	15.5 ± 1.9	- 0.2.464*	.020
Female (n=17)	17.3 ± 1.9		
External Support			
Male (n=13)	9.8 ± 2.1	-.854	.400
Female (n=17)	10.6 ± 2.5		
Caregiver routine			
Male (n=13)	9.0 ± 1.3	.294	.771
Female (n=17)	8.8 ± 1.8		
Support of Patient			
Male (n=13)	8.5 ± 1.9	.530	.600
Female (n=17)	8.2 ± 1.0		
Taking responsibility			
Male (n=13)	9.3 ± 1.3	-.510	.614
Female (n=17)	9.5 ± 1.1		
Other relations			
Male (n=13)	5.8 ± 1.7	-.614	.544
Female (n=17)	6.2 ± 1.8		
Patient's Behaviour			
Male (n=13)	8.5 ± 1.8	-1.655	.109
Female (n=17)	9.5 ± 1.3		
Care giver strategy			
Male (n=13)	7.84 ± 1.07	-.976	.337
Female (n=17)	8.35 ± 1.62		
Burden (Total)			
Male (n=12)	82.58 ± 9.59	-1.041	.308
Female (n=15)	86.47 ± 9.66		

Table 7: *Co- relation of Level of Burden in Caregivers with age & number of hospitalizations (n=30, * p<0.05, ** p<0.01)*

Variable	Spouse related	Physical & mental health	External support	Caregiver routine	Support of patient	Taking responsibility	Other relations	Patient's behavior	Caregiver's strategy	Total
Age of Patient	.45*	-.001	.078	-.23	.24	.07	.18	-.29	.06	.14
No. of Admission	.14	.07	-.06	.14	.41*	.23	.00	.16	.10	.20

Table 8: *Co- relation between Domain scores of BASS (n=30, * p<0.05, ** p<0.01)*

Variable	**Spouse related**	**Physical & mental health**	**External support**	**Caregiver routine**	**Support of patient**	**Taking responsibility**	**Other relations**	**Patient's behavior**	**Caregiver's strategy**	**Total**
Spouse related	1	.11	.27	.01	.15	.35	.41*	.11	.18	.50*
Physical & Mental Health	.11	1	.47*	.43*	.08	.27	.32	.46*	.50*	.69*
External support	.27	.47*	1	.47**	.13	.51**	.33	.33	.39*	.78**
Caregiver Routine	.01	.43*	.47**	1	-.12	.30	.24	.37*	.39*	.61**
Patient support	.15	.08	.13	-.12	1	.31	-.07	.36	.014	.30
Taking responsibility	.35	.27	.51**	.30	.31	1	.32	.57**	.30	.68**
Other relations	.41*	.32	.33	.24	-.07	.32	1	.14	.30	-55**
Patient behavior	.11	.46*	.33	.37*	.36	.57**	.14	1	.40*	.67**
Caregiver strategies	.18	.50**	.39*	.39*	.01	.30	.30	.40*	1	.65**
Total Burden	.49**	.69**	.78**	.61**	.30	.68**	.55**	.67**	.65**	1

4. Discussion

While 43.3% of the caregivers were males, 56.7% were females; 80% were married and 20% were single; 80% were Hindus, 10% were Muslims and 10% Christians. While 50% of the patients were diagnosed as BPAD with severe depression, the rest 50% were diagnosed as RDD & moderate depression. The mean age of the patients was 36.7 ± 16.3. By the year 2020, depression is projected to reach second place in the ranking of Disability Adjusted Life Years (DALY) calculated for all ages. Today, depression already is the second cause of DALYs in the age category 15-44 years [31]. 30% of the patients had first episode of the illness and for 33.3% of them this was the first admission. Caregivers age ranged from 16-67 years with Mean age of 42.9 ± 15.5 reflecting that caregivers were in their most productive ages. Mariann Idstad, Helga Ask and Kristian Tambs [27] reported that the caregivers Mean age was 53.4 years (SD = 14.42) for men and 50.8 years (SD = 14.26) for women. The subjective burden levels ranged from 67-98 and Mean Burden was 84.7 ± 9.7. A score of 40 on the BASS would indicate no burden, 80 moderate burden and 120 extreme burden. Increasing scores indicate increasing levels of burden.

Individual domain standardized percentage scores indicated highest burden in the domain of physical & mental health (67.9), taking responsibility (67.5), patients' behaviour (63.8), and caregivers' routine (61.3). Indian families are very close knit and perhaps hence standardized percentage scores seemed to be comparatively less in the other domains such as support of patient (53.8), caregivers strategy (51.3), other relations (50.0), spouse related (46.3) and external support (35.8). Research on caregiver burden noted that spouses of depressed persons reported higher levels of symptoms of anxiety and depression and lower levels of subjective well-being [27]. In a review [32] on Psychiatric symptoms in caregivers of patients with bipolar disorder, it was observed that among the 24 papers that were analyzed, 46% of caregivers reporting depression and up to 32.4% reporting mental health service use. Mean Burden level in female caregivers (17.3) was significantly (p<0.05) higher than in male caregivers (15.5). Similar findings of gender differences with more burden perception by female caregivers have been reported in other studies [27, 29]. There is a correlation between the patient's age and spouse related burden as well as between number of hospital admissions and burden related to support of patient. Leinonen E., Korpisammal L., Pulkkinen L.M., Pukuri T. reported that no correlation was found between stress of the spouse and her or his own age or the age of the patient either within the depressive or within the demented group [30]. High burden levels could predispose to depression, substance abuse, anxiety, etc. in caregivers of patients with depression. This study results indicate the need for family based interventions addressing this issue.

4.1 Methodological Considerations

The subjects for this study were selected from a clinical population. This may have contributed to a higher level of burden perception since patients are admitted only in the acute stage of illness. Small sample size and convenience sampling technique detract from the generalizability of the findings and necessitate that the findings be treated with caution. Research can be conducted on larger sample sizes, in the community, different cultures and also compare caregiver burden between care recipients' of different mental illness.

5. Conclusion

Depression is rapidly becoming a millennium illness that has to be reckoned. In India, especially, nuclear family pattern is becoming a vogue today. Caregivers of persons with mental illness were supported by the joint family system in earlier days. However, today caregivers are more burdened because of reduced family support owing to the nuclear family pattern and this can contribute to depression, anxiety and raised stress levels. Nurses can help family caregivers to identify their negative experiences about care-giving and can help them reflect upon their coping strategies to find balance in their situation. There is a need for psycho-social interventions addressing caregiver burden issues.

Acknowledgements

The authors acknowledge the contributions of the caregivers who participated in the study and the administrative authorities who permitted data collection.

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