

Subjective Burden among Caregivers of Patients with Mental Illness: A Cross-Sectional Study

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Abstract

Background and Objectives: Caregivers play a vital role in supporting family members who are sick, infirm or disabled. Patients with mental illness are dependent on their caregiver and their well being is directly related to the nature and quality of the care provided by the care giver. Caring for a mentally ill individual is burdensome due to the quantum of effort needed to satisfy both their physical and psychological needs. Hence, this study was undertaken with an objective to determine the level of subjective burden among the care givers of patients with mental illness. *Materials and Methods:* This study was conducted among the care givers of the patients with mental illness attending the psychiatric out patient department of a tertiary care hospital. A cross sectional descriptive study design was adopted. The sample size was 178 subjects. Caregivers of the mentally ill were chosen through non-probability convenient sampling method. The caregiver burden was assessed using the Zarit Burden Interview. *Results:* The result of this study revealed that, among the 178 subjects, a vast majority of subjects (82%) had subjective burden and only 17.9% had experienced no burden. Among the 146 subjects who reported to have care giver burden, about 66 (45.2%) subjects had mild burden; 63 (43.2%) had moderate burden and only 17 (11.6%) subjects had severe burden. *Conclusion:* It was evident from the present study that at any given point of time, a majority of caregivers of patients with mental illness experienced burden in some form. Hence it is imperative that alleviating the burden among caregivers should be given importance in order to achieve better clinical outcome. *Interventional*

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programs exclusively developed for care givers will help them to manage the burden effectively. Psychiatric nurses must give priority in addressing the burden of caregivers in their routine patient care.

Keywords: Caregiver; Patients with Mental Illness; Caregiver Burden.

Introduction

Successful management of mental illness relies significantly in on unformed or non-professional networks of caregivers. Caregiver's burden is a multi-dimensional phenomenon reflecting physical, psycho-emotional, social and financial consequences of caring for an impaired family member. Caregivers may experience financial burden, difficulty in handling the disruptive behavior and fluctuating emotions that cannot be controlled, a lack of time for personal enjoyment and social engagement, difficulty in handling the lack of motivation found in family members. Addition of the caregiving role to the already existing family role may become stressful, both psychologically and economically [1].

Research studies undertaken pertaining to this area reveal that caregiver burden is one of the most important issues that need to be tackled with utmost intricacy like that of the mental illness. The results of a community based study which was conducted in a rural area showed that the burden among caregivers in general was higher than expected and it became lower, due to the interventions given through a community based programme [2]. In another descriptive analytic study, which was conducted on family caregivers of patients with mental disorders using a 22-item Zarit Burden Interview, it was found that 73.6% of family care givers experienced moderate to severe level of burden. This study also concluded that professional interventions should be offered

especially to those caregivers of patients with mental illness who experienced burden and stress [3].

The investigator from his clinical experience found that most of the times, the primary focus of attention of the mental health team members is only on the patients, while the caregivers remain unnoticed. This issue instigated the investigator to take up this study and it was firmly believed that the results of this study would pave way for formulating a referral system with nursing interventional program for caregivers with perceived burden.

Materials and Methods

This study was conducted among the care givers of the patients with mental illness, who were attending the psychiatric out patient department of a tertiary care hospital.

The objectives of this study were to assess the level of subjective burden among the caregivers and to find association of the over all subjective burden and severity of the burden with the socio-demographic and clinical variables. The quantitative research approach with a cross-sectional descriptive study design was adopted. The sample size for this study was 178 (caregivers of the patients with mental illness) and this sample size was estimated with an expected prevalence of perceived burden among caregivers as 49% at 5% level of significance and 15% relative precision. The subjects were chosen based on non-probability convenient sampling method. The sample selection criteria were: caregivers of both the sex, aged between 19 and 65 years and who had rendered care by staying with the patient for a minimum of 6 months. Face to face structured interview technique was used to collect the data, with the following instruments.

Part I: Guide for Collecting the Socio-Demographic and Clinical Variables

This included the caregiver's age, gender, educational status, occupation, locality, monthly income, marital status, relationship with the patient, type of mental illness and duration of stay

Part II: Zarit Burden Interview (ZBI)[4]

Zarit Burden Interview scale was developed to measure the subjective burden among caregivers of adults with mental illness. The ZBI is a standardized tool and reliability was assessed by excellent internal consistency. Items were generated based on studies resulting in a 22 items self-inventory that examines burden associated with functions or behavioral impairment and home care situation.

Each item was rated as follows:

- 0 - Never
- 1 - Rarely
- 2 - Sometimes
- 3 - Quite frequently
- 4 - Nearly always

The score were interpreted as follows:

- 0 - 21: Little or no burden
- 21 - 40: Mild to moderate burden
- 41 - 60: Moderate to severe burden
- 61 - 88: Severe burden

Results

The data were analyzed using the SPSS version 22. The descriptive (frequency, percentage) and inferential statistics (chi-square test) were computed. The results of the study were discussed as follows,

Table 1 denotes that 146 (82%) subjects reported that they had caregiver burden with different levels (mild to moderate burden - 67 (37.6%); moderate to severe burden - 62 (34.8%); severe burden - 17 (9.6%) and only 39 (18%) of the remaining subjects had little or no burden, as measured by the Zarit Burden Interview Scale.

Table 2 shows the association of the overall subjective burden with the socio-demographic and clinical variables. It was identified that, a 146 (82%) subjects experienced care giver burden, where as only 32 (17.9%) subjects had not experienced care giver burden. A statistically significant association was

Table 1: Distribution of the level of subjective burden among the caregivers of patients with mental illness (N = 178)

S. No.	Categories	Frequency	Percentage
1.	Little or no burden	32	18%
2.	Mild to moderate burden	67	37.6%
3.	Moderate to severe burden	62	34.8%
4.	Severe burden	17	9.6%

found between the age, gender, educational status and over all subjective burden among the care givers.

Table 3 indicates the association of the severity of subjective burden with the socio-demographic and clinical variables. Among the 146 subjects who reported to have care giver burden, a majority of about

66 (45.2%) subjects had mild burden 63 (43.2%) had moderate burden and only 17 (11.6%) subjects had severe burden. A statistically significant association found between the age, occupation, locality of the subjects and the severity of subjective burden.

Table 2: Association of the over-all subjective burden among care givers with the socio-demographic and clinical variables. (N = 178)

Variables	Over-all subjective burden among care givers				χ^2	p Value
	No (Score: 0 - 20)		Yes (Score: 21 - 88)			
	f	%	f	%		
Age						
18 - 25	7	3.9	10	5.6	6.9	0.032*
26 - 50	5	2.8	79	44.4		
51 - 65	10	5.6	57	57		
Gender						
Male	17	9.6	63	35.4	1.05	0.03*
Female	15	8.4	83	46.6		
Educational status						
Primary	16	8.9	102	57.3	12.71	0.002**
Secondary	7	3.9	34	19.1		
Graduate & above	9	5.1	10	5.6		
Occupation						
Employed (Govt./Private)	6	3.4	40	22.5	1.06	0.59
Self-employed	11	6.2	59	33.14		
Unemployed	15	8.4	47	26.4		
Locality						
Urban	16	8.9	50	28.1	2.8	0.09
Rural	16	8.9	96	53.9		
Monthly income						
≤5000	24	13.5	121	67.9	1.08	0.29
>5000	8	4.5	24	13.5		
Marital Status						
Single	6	3.4	15	8.2	2.01	0.36
Married	24	13.4	117	65.7		
Divorced / Separated	1	0.6	1	0.6		
Relationship with the patient						
Parent	11	6.2	48	26.9	6.56	0.16
Sibling	6	3.4	9	5.1		
Spouse	7	3.9	54	30.3		
Son / daughter	8	4.5	8	4.5		
Type of mental illness						
Organic disorder	0	0	19	10.6	9.94	0.08
Schizophrenia	4	2.2	21	11.7		
Mood disorder	25	14.04	77	43.3		
Psychoactive substance use disorder	2	1.1	12	6.7		
Mental retardation	1	0.6	6	3.4		
Other disorders	0	0	11	6.2		
Duration of stay with the patient						
6 months - 2 years	8	4.5	35	19.6	0.01	0.09
> 2 years	24	13.5	111	62.4		

*Significant at p<0.05 ; **Significant at p<0.005

Table 3: Association of the severity of subjective burden among care givers with the socio-demographic and clinical variables (N = 146)

Variables	Severity of subjective burden among care givers						χ^2	P Value
	Mild to moderate		Moderate to severe		Severe			
	f	%	f	%	f	%		
Age								
18 - 25	9	6.2	0	0	1	0.6	9.9	0.04*
26 - 50	34	23.3	37	25.3	8	5.5		
51 - 65	23	15.7	26	17.8	8	5.5		
Gender								
Male	31	21.2	27	18.5	5	3.4	1.7	0.42
Female	35	23.9	36	24.6	12	8.2		
Educational status								
Primary	40	27.4	49	33.5	13	8.9	5.6	0.22
Secondary	19	13	12	8.2	3	2.1		
Graduate & above	7	4.7	2	1.4	1	0.6		
Occupation								
Employed (Govt./Private)	24	16.4	15	10.3	1	0.6	11.8	0.02*
Self-employed	18	12.3	13	20.5	11	7.5		
Unemployed	24	16.4	18	2.3	5	3.4		
Locality								
Urban	31	21.2	16	10.9	3	2.1	9.02	0.01*
Rural	35	23.9	47	32.2	14	9.5		
Monthly income								
≤5000	51	34.9	54	36.9	16	10.9	3.3	0.18
>5000	15	10.3	9	6.2	1	0.6		
Marital Status								
Single	11	7.5	2	1.4	2	1.4	8.2	0.08
Married	49	33.5	56	38.3	12	8.2		
Divorced / Separated	6	4.1	5	3.4	13	2.1		
Relationship with the patient								
Parent	21	14.3	21	14.3	6	4.1	3.6	0.09
Sibling	2	1.4	6	4.1	1	0.6		
Spouse	28	19.2	21	14.3	5	3.4		
Son / daughter	15	10.2	15	10.3	5	3.3		
Type of mental illness								
Organic disorder	8	5.5	9	6.2	2	1.4		
Schizophrenia	12	8.2	7	4.7	2	1.4	8.2	0.06
Mood disorder	36	24.6	34	23.3	7	4.7		
Psychoactive substance use disorder	3	2.1	6	4.1	3	2.1		
Mental retardation	2	0.1	2	1.4	2	1.4		
Other disorders	5	3.4	5	3.4	1	0.6		
Duration of stay with the patient								
6 months - 2 years	17	11.6	16	10.9	2	1.4	1.6	0.05
> 2 years	49	33.6	47	32.2	15	10.3		

*Significant at p<0.05

Discussion

The findings of the present study clearly revealed that caregiver burden is present among majority of the subjects and it is one of the important aspects that need to be taken into consideration. As far as the level of subjective burden among caregivers of patients with mental illness is concerned, this study demonstrated that majority of subjects (82%) reported that they had caregiver burden and only 18% of the remaining

subjects had little or no burden. These findings are in relevance with a study done by Anjum et al [5], who had studied the burden of care and associated mental health problems in caregivers of patients with schizophrenia at Lahore. They had found that a majority of 55% of caregivers had higher level of burden and associated mental health problems.

Among the subjects who had reported to have subjective burden, the severity of the burden had been figured out in the current study as: mild to moderate

burden – 37.6%; moderate to severe burden – 34.8%; severe burden – 9.6%. These findings are supported by a study done by Chen et al [6] which showed that caregivers of patients with different psychiatric illnesses had moderate burden and higher burden scores were correlated with a lower quality of life. On the contrary, these findings were different from findings of a study done by Bello-Mojeed et al [7], who reported that 41.3% subjects had no or little burden, 33.5% of subjects had mild to moderate burden, 22% had moderate to severe burden and 3.2% had severe burden.

In the present study, it was found that there was a statistically significant association between the age, gender, occupation, educational status, locality of the subjects and the subjective burden of caregivers. These findings are consistent with studies done by Gandhi et al [8], and Srivastava [8] who stated that high burden level was present among female caregivers and among caregivers from rural locality.

Conclusion

This study had clearly indicated that burden among caregivers of patients with mental illness is inevitable. Addition of caregiving role to the already existing role may become burdensome and stressful both physically and psychologically [10]. Mental health team members must understand the fact that family caregivers form an integral part of holistic management of patient care and they often have to contend with the physical, emotional, social and financial strains of caregiving. Though caregiver burden has been considered as a neglected part of research in mental health care, these days studies are being undertaken to break the mystery in relation to this area. Hence, the current study would certainly throw light among the mental health professionals, especially nurses signifying the importance of paying attention to caregivers, while

providing comprehensive care for the patients with mental illness.

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