International Journal of Science and Research (IJSR)
ISSN (Online): 2319-7064
Index Copernicus Value (2015): 78.96 | Impact Factor (2015): 6.391

Assessment of Caregiver Burden in Psychiatric Patients

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Abstract: ***This study aims to assess the prevalence of caregiver burden in psychiatric illnesses, assessing gender differences in caregiver burden, correlating the duration of psychiatric symptoms & relationship of caregiver with patient, to the severity of burden. 45 caregivers of patients with psychiatric illness were assessed on Zarit caregiver Burden interview scale &Dass 42 scale. Caregiver burden was prevalent in all patients, with greater burden perceived by females than by males . Longer duration of illnesses were associated with greater burden perceived. Parents of patients and spouses experienced greater burden followed by the children & siblings respectively.***

Keywords: caregiver, burden, psychiatric illness.

1. Introduction

Recent years have seen increasing awareness of the role of caregivers in the long-term management of psychiatric patients, and there is growing body of literature on the caregiver burden, poor caregiver outcomes, lack of caregiver support, and equivocal success, with interventions aimed at alleviating the care-giving burden. It has also become clear that the emphasis in psychiatric rehabilitation needs to shift from a patient-focused approach to a combined patient and caregiver- focused approach.

Caregiving is a dynamic process which includes patient, and a person who is involved in long term care of the patient. In disabling mental disorders such as schizophrenia and bipolar disorder, long term care is involved. This long term care very often leads to experience of burden in the caregivers.

2. Literature Review

Hoeing and Hamilton[1]were the first researchers to make a distinction between objective and subjective dimensions of burden. Objective burden (OB) refers to the negative effects of the illness on the household and the caregiving demands placed on the family members. Subjective burden (SB) refers to the caregivers’ or family members’ personal appraisals of the situation and the extent to which the individuals perceive they are carrying a heavy load. [2]

Caregiver burden can include physical, psychological, social, and financial problems. [3,] embarrassment; overload; and resentment.[4]Caregiver responses vary with their relationship to the recipient. Spouses are at risk because of their own physical frailties and loss of support.[5] Alternatively, caring for a spouse may be viewed as a marriage commitment, but caring for a parent may produce conflicts with a spouse and/or children.[6]Gallagher and associates11 found that 36% of caregivers who were not seeking help had clinical depression, compared with 68% of self-referred caregivers.[7] Several studies have shown that female caregivers experience more distress than their male counterparts and that this finding persists even after controlling for the influence of other variables such as income and education. [8-10.]

Greater burden was predicted by more severe patient negative symptoms (stressor), greater anger control (vulnerability), and decreased tangible social support (resource).

In a study, Trivedi and colleagues[11] found that the parents and siblings of schizophrenic patients experienced more burden in comparison to spouses. They also stated that young relatives and those having the age of above 45 experienced more burden than the middle age group relatives. There is a positive correlation of family burden and duration of illness. [12]

The onset of Bipolar disorder in an adolescent presents potentially lifelong care giving challenges for the parents. Parents may provide decades of extended care giving challenges for the adult son or daughter who is suffering from BPAD when debilitating symptoms produce ongoing obstacles to social and occupational functioning and independent living. This chronic care giving role may cause stress for parents and threaten their physical and mental health. Bipolar disorder is associated with a high degree of chronicity and disability, and caregivers experience a significant burden, which is, in turn, associated with poorer clinical outcomes for the patients. The burden experienced by caregivers for BPAD patients is independently predicted by patients’ depression, even after taking into account the chronicity of symptoms.

Patients with disorders such as schizophrenia and bipolar affective disorder are more likely to relapse when there is high expressed emotion present in their living environment. The stress from the remarks and attitudes of the family is overwhelming because they feel like the cause of the problems. The patient then falls into the cycle of relapse. The only way to escape this vortex is for the family to go through therapy together to prevent the criticism and relapse. But before that it becomes necessary to understand that what is the reason behind such attitude towards a family member who is mentally ill, what is the cause of burden and what all changes the caregivers' and the patients' quality of life come across.

3. Method

This was a Cross Sectional , analytical study conducted among patients attending the Psychiatric OPD/IPD at BharatiVidyapeeth Deemed Univeristy Medical College and Research Centre; a private tertiary care hospital in Pune , India . A total of 45 caregivers, all above the age of 18 years, of patients with psychiatric diagnosis of schizophrenia, mood disorders, substance use disorders as per International Classification of Diseases and Health Related Problems- 10 (ICD-10) were included. Caregivers having pre-existing psychiatric illnesses and other co-existing medical or surgical illnesses as well as Caregivers of patients having co-existing medical or surgical illnesses and having other diagnosed psychiatric conditions other than schizophrenia, substance use disorders, mood disorders were excluded.A written informed consent was taken from all participants.

After Obtaining Sociodemograhpic details of the participants like age, gender , education, occupation, relation with patient , family type , marital status , etc., the perceived burden of the caregivers was measured using the Zarit Burden Interview Scale , a popular caregiver self-report measure used by many aging agencies, originated as a 29-item questionnaire (Zarit, Reever& Bach-Peterson, 1980).The revised version contains 22 items. Each item on the interview is a statement which the caregiver is asked to endorse using a 5-point scale. Response options range from 0 (Never) to 4 (Nearly Always).

The DASS 42 is a set of three self –report Scales designed to measure the negative emotional states of depression, anxiety and stress. Based on a dimensional rather than categorical conception of a psychological disorder , the development of DASS was based on the assumption that the depression , the anxiety and the stress experienced by the normal and the clinically disturbed , are essentially differences in degree. The DASS is available in English, Hindi and Marathi , translation there of has been done by a team at KEM hospital , Pune. Psychological disturbances in participants were assessed on the scores obtained on DASS 42. Chi-Square test, Fischer's Exact- test were used to obtain the results.

4. Results

Out of a total of 45 participants , 19 were females and 26 were males. A certain degree of burden along with varying degrees of stress, anxiety and burden was perceived by all participants. 56% of caregivers displayed moderate burden , 9% mild burden and around 35% of patients having severe burden . However, females perceived a great level of burden compared to men (p=0.322). They also had a mariginally greater amount of anxiety (p=<0.001), stress (p=0.018) and depressive features (p=0.056) compared to men.

22 participants had their patients with duration of illness of less than 1 year, 13 had between 1-5 years, while 10 caregivers had their patients with duration of illness of more than 5 years. The duration of illness showed a directly proportionally relation with respect to the burden perceived by the caregivers. Caregivers of patients with longer duration of illness, showed a great amount of burden (p=0.162). They also perceived a greater amount of depressive features (p=0.811) and stress (p=0.932). Anxiety (p=0.955)however was seen more among caregivers of patients with comparatively shorter duration of illnesses

The Caregivers were the parents, the siblings, the children or the spouses of the patients. With respect to the relationship of the caregiver with the patient, parents of patients and spouses experienced greater burden followed by the children and siblings respectively (p=<0.001). Depressive and stress symptoms (p=<0.001) were greatest in the spouse , followed by the parents , and then children and siblings respectively. The parents and spouse have equal levels of anxiety (p=0.005,) followed by the children and then lastly the siblings of the patients.

		Gender		Total	p-value
		F	M		
zarit severity	mild	11	5	16	0.322
	moderate	14	11	25	
	severe	3	1	4	
Total		19	26	45	

		Gender		Total	p-value
		F	M		
dass anxiety grade	Extremely severe	1	0	1	< 0.001
	mild	9	9	18	
	moderate	8	3	11	
	severe	1	0	14	
	normal	0	14	1	
Total		19	26	45	

		Gender		Total	p-value
		F	M		
zarit severity	Mild	11	5	16	0.322
	Moderate	14	11	25	
	Severe	3	1	4	
Total		19	26	45	

		Gender		Total	p-value
		F	M		
dass anxiety grade	Extremely severe	1	0	1	< 0.001
	mild	9	9	18	
	moderate	8	3	11	
	severe	1	0	14	
	normal	0	14	1	
Total		19	26	45	

		Gender		Total	p-value
		F	M		
dassdep grade	extremely severe	1	0	1	0.056
	mild	11	6	17	
	moderate	7	6	13	
	normal	1	7	8	
	severe	5	1	6	
Total		19	26	45	

		Gender		Total	p-value
		F	M		
dass stress score	extremely severe	1	0	1	0.018
	mild	6	11	17	
	moderate	6	6	12	
	normal	0	7	7	
	severe	6	2	8	
Total		19	26	45	

		Duration_Group			Total	p-value
		<1 year	1-5 years	> 5 years	Total	p-value
Zarit severity	mild	1	4	11	16	0.162
	moderate	7	8	10	25	
	severe	1	1	2	4	
Total		22	13	10	45	

		Duration_Group			Total	p-value
		<1 year	1-5 years	> 5 years		
dass anxiety grade	Extremely severe	1	0	0	1	0.955
	mild	10	5	3	18	
	moderate	5	3	3	11	
	normal	5	5	4	14	
	Severe	1	0	0	1	
Total		22	13	10	45	

		Duration_Group			Total	p-value
		< 1 year	1-5 years	> 5 years		
Dassdep grade	extremely severe	1	0	0	1	0.811
	mild	3	6	8	17	
	moderate	4	4	5	13	
	normal	1	1	6	8	
	severe	1	2	3	6	
Total		22	13	10	45	

		Duration_Group				p-value
		< 1 year	1-5 years	> 5 years	Total	
Dass stress score	Extremely severe	0	0	1	1	0.932
	mild	4	5	8	17	
	moderate	3	4	5	12	
	normal	5	1	1	7	
	severe	2	2	4	8	
Total		22	13	10	45	

		Relation					
		parents	siblings	children	spouse	Total	p-value
zarit severity	mild	3	8	3	2	16	< 0.001
	moderate	10	0	5	10	25	
	severe	0	0	0	4	4	
Total		13	8	8	16	45	

		Relation				Total	p-value
		Parents	Siblings	Children	Spouse		
dass anxiety grade	Extremely severe	0	0	0	1	1	0.005
	mild	6	2	4	6	18	
	moderate	2	0	1	8	11	
	normal	5	6	3	0	14	
	Severe	0	0	0	1	1	
Total		13	8	8	16	45	

		Relation				Total	p-value
		Parents	Siblings	Children	Spouse		
dassdep grade	Extremely severe	0	0	0	1	1	< 0.001
	mild	7	2	8	0	17	
	moderate	4	0	0	9	13	
	normal	2	6	0	0	8	
	severe	0	0	0	6	6	
Total		13	8	8	16	45	

		Relation				Total	p-value
		Parents	Siblings	Children	Spouse		
Dass stress score	extremely severe	0	0	0	1	1	< 0.001
	mild	5	3	8	1	17	
	moderate	6	0	0	6	12	
	normal	2	5	0	0	7	
	severe	0	0	0	8	8	
Total		13	8	8	16	45	

		diagnosis of primary pt				Total	p-value
		ADS (n=15)	Mood disorder with psy (n=4)	Mood disorder (n=11)	schizophrenia (n=15)		
zarit severity	mild	3	2	8	3	16	0.079
	moderate	10	2	3	10	25	
	severe	2	0	0	2	4	
dass anxiety grade	mild	4	2	4	8	18	0.228
	moderate	4	1	2	4	11	
	Severe	0	1	0	0	1	
	extremelysevre	0	0	0	1	1	
	normal	7	0	5	2	14	
dassdep grade	mild	6	2	4	5	17	0.262
	moderate	5	1	1	6	13	
	severe	2	0	1	3	6	
	extremely severe	0	0	0	1	1	

	normal	2	1	5	0	8	
dass stress score	mild	7	2	4	4	17	0.118
	moderate	4	1	2	5	12	
	severe	2	1	0	5	8	
	extremely severe	0	0	0	1	1	
	moderate	4	1	2	5	12	

5. Discussion

These findings demonstrate that almost all the caregivers of patients with psychiatric illnesses experience some form of burden and also display symptoms of anxiety, depression and stress in varying levels. Also females displayed a greater burden compared to males. The duration of the illness was directly proportional to the severity of the burden. Anxiety however was seen more in illnesses with shorter duration , unlike depressive and stress symptoms. Spouse and parents of patients experienced greatest burden and psychological symptoms , followed by children and lastly siblings.

6. Future Scope

Chronic caregiving role may cause stress for the caregivers and threaten their physical and mental health , which go unaddressed leading to worsening of their own health as well as the health of the primary patients .

Patients with psychiatric disorders are more likely to relapse when there is high expressed emotion present in their living environment. The stress from the remarks and attitudes of the family is overwhelming because they feel like the cause of the problems. The patient then falls into the cycle of relapse. The only way to escape this vortex is family counseling and psychoeducation to prevent this relapse. It is also imperative to identify and address caregiver burden and stress and thus prevent a psychological breakdown in the caregivers themselves

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