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Original Research Article

Comparison of stressful life events among family caregivers of cancer, mental retardation and schizophrenia patients leading to stress, anxiety and depression and its effect on quality of life

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ABSTRACT

Background: Mental retardation (MR), schizophrenia and cancer are chronic disorders, requiring long term treatment along with family support. Principal caregiver is usually nonprofessional family person who play a pivotal role in supporting the patient medically, emotionally and financially which in turn affects their own health and quality of life. To identify stressful life events, level of anxiety, stress, depression and Quality of life in these family caregivers (FC), this study was planned.
Methods: After gaining consent, the FC were assessed on Presumptive Stressful Life Events Scale (PSLE), Depression Anxiety Stress Scale (DASS) and WHO Quality of Life -Bref Scale (WHOQOL-Bref). Data so gained was analyzed by SPSS-21 and results were drawn.
Results: 66 FC of cancer patients, 39 FC of MR patients and 53 FC of Schizophrenia patients were assessed. All three groups were found to be matched socio-demographically. On PSLE Mean of total stressful life events for cancer FC was 7±1.5, for MR 6.02±1.5 and for schizophrenia FC was 5.75±1.70 and this difference was statistically significant. Mean of total undesirable life events was 5.31±1.3, 4.33±1.34 and 3.86±1.46 respectively and this difference was also statistically significant. Similarly difference in mean stress score of total life events and for undesirable events was also statistically significant. On DASS scale no statistically significant difference was found within the groups. Quality of life was significantly low depicting high impact on physical health and social life of these care givers.
Conclusions: Family Caregivers of cancer, mental retardation and schizophrenia groups are highly affected and there is urgent need to address these issues for early diagnosis and treatment.

Keywords: Anxiety, DASS, Depression, Family Caregivers, PSLE, Stress, WHOQOL-BREF

INTRODUCTION

Care giving and care receiving can occur at any point in the life-course and is typically associated with chronic illnesses or disabilities. It results in loss of independence and disturbance in proper day-to-day functioning of the caregiver. There is no standard definition of family care giving which can be used consistently from one study to another.[1] What the term care giving means is not always clear and frequently varies with the purpose for which such definitions are used.[2]

Focus on the role of family in the life of a person with different physical or mental disorders has been dual. Earlier the focus had been on the possible etiological role of the family in disease, now it seems to be a paradigm shift and family now is being perceived as a "reactor" to disease of a member.[3] Family is the main source of support for the persons with disabilities in any society.[4] With advancement in the medical sciences in prolonging the life of a diseased person and increasing change in health policies to integrate the persons with illness in the community, family care giver has now become a major

stake holder in overall management.[5] Family is defined as a group of individuals who live together during important phases of their life time and are bound to each other by biological and/or social and psychological relationship.[6]

Family Caregivers (FC) are mostly the patient's spouse, parents or closest relatives but significant others can also take on that role and function. Family caregiver is often subjected to multiple sources of stress.[7]

FC is essential to the care of patients with cancer. Patients with cancer often require assistance from friends and family in addition to the care from their medical team.[8] Specifically, FC help patients with transportation, finances, personal care, emotional support, and symptom management.[9] There is a trend towards early discharge of hospitalized cancer patients to their private homes, thus leaving more of the care to the persons closest to the patient.[10-12] This trend is in line with the fact that many patients with advanced cancer, and their families, prefer home care instead of admission to nursing homes or long-term hospitalization.[13-16]. At home the FC is the main provider of physical and emotional support for the patient.[17]

Despite the critically important care they provide to patients, FC often experience negative physical and psychological consequences themselves related to care giving demands.[18-21] Prior studies of FC of cancer patients have shown that they report a substantial symptom burden, including fatigue and sleep disturbance.[22]

Mental retardation (MR) is one of the most prevalent developmental disability. Those who are closest to the persons with MR and care for them bear the brunt of their disability. Families experience enormous physical and emotional burden whilst caring for such relatives.[23-27] Poor performance by the person with disability, be it physical, psychological or social, needs to be compensated by the caregivers and for up to life long as this disease is untreatable. This leads to unavoidable stress and psychological trauma among the families. Few patients have behavioral problems such as destructibility, temper tantrum, odd behavior leading to extra burden.

Schizophrenia is one of the chronic psychiatric illnesses demanding long term care in term of repeated admissions, multiple treatments, ECT etc. Unproductiveness, irrational behavior and sometimes aggression add the problems to the FC.

In a study that assessed caregiver burden in patient suffering from schizophrenia, the overall burden was found to be moderate and most burdensome areas were of finance and family dynamics. Stress level was also found to be high among caregivers of Schizophrenia.

Factors like duration of illness, being in debt, lower education level, married, subjective feeling of psychological stress and self-realization of need of medical help were found to be significantly associated with higher level of stress.[28]

In this country family culture is very strong and professional care givers such as half way home and sheltered accommodation, nursing care homes are very less, especially in this area, so all the burden of care giving is shouldered by FC.

Successful management of major illness in the community relies significantly on an informal or non-professional network of caregivers. The needs and experiences of such caregivers have been little studied with respect to major chronic disorders.

This study was conducted to find the stressful life events, determine the prevalence of stress, depression and anxiety and Quality of life of family caregivers of cancer, mental retardation and schizophrenia patients. By assessing the caregiver's level of burden including emotional problems, these carers who are at high risk can be identified early and managed accordingly.

METHODS

The study was conducted at the Tertiary care level hospital of India. Purposive sampling was done and total of 158 subjects between 16 August 18 to 30 August 18 were screened on inclusion and exclusion criterions, which included 66, 39 and 53 caregivers of cancer, mental retardation and schizophrenia patients respectively. Mainly the subjects were the parents of the children with well-established diagnosis of MR, family members of cancer patients and schizophrenia.

Inclusion criteria

- Age >18 Years and willing to give informed consent.
- Relative of patient.
- Living with the patient in same environment for at least last 12 months.
- Directly involved in the care of the patient.

Exclusion criteria

- Caregivers reported to having serious medical illness impairing physical health which can affect their psychological wellbeing and increase the risk.
- Younger age caregivers (below 18) as they may not be able to understand the concept of care giving, nature and consequences of illness, medication issues etc. and tend to report more stress and increased burden.

A semi-structured proforma was used to collect socio-demographic details including variables such as age, gender, education, occupation etc. FC were then assessed on PSLE, DASS, WHOQOL-Bref to assess stressful life events, depression, anxiety, stress and Quality of Life.

Statistical analysis was then done using SPSS software (ver.21).

RESULTS

Description of tools

Semi-structured proforma

Contains socio-demographic detail of FC.

Presumptive stressful life events (PSLE)

This scale was developed by Singh et al, in 1981 for assessing stressful life events for Indian patients by using open-ended questionnaire. It was based on fruitful collaboration of Holmes and Rahe, who believed that some kind of a list of commonly encountered stressors would be more useful than the relatively unregulated process of taking an unstructured history. After considerable research, they developed a list of 51 life events relevant to Indian conditions, ranging from death of a spouse to going on a pleasure trip/pilgrimage. Scale items are classified into desirable, undesirable and ambiguous. Each item has its own specific mean stress score.

Depression anxiety stress scale (DASS)

In this study we have used DASS to quantify burden in caregivers. The DASS is a 42 item questionnaire having 3 parts designed to measure anxiety, stress and depression. Each of the 3 part contains 14 items. Respondents are asked to use 4 point likert scales to rate the extent to which they have experienced each state over the past week (Table 1).

WHOQOL-BREF (1995)

This is the shorter version of WHO-QOL 100. Authors used Hindi version developed by Dr. Shekhar Saxena. This questionnaire consists of 26 questions divided into four domains namely Physical, Psychological, Social and Environmental. Questionnaire is rated on a five point rating scale. Questions are scored as 1, 2, 3, 4 and 5 while question 3, 4 and 26 are scored in reverse frame. The four domain scores denote an individual's perception of quality of life in each particular domain.

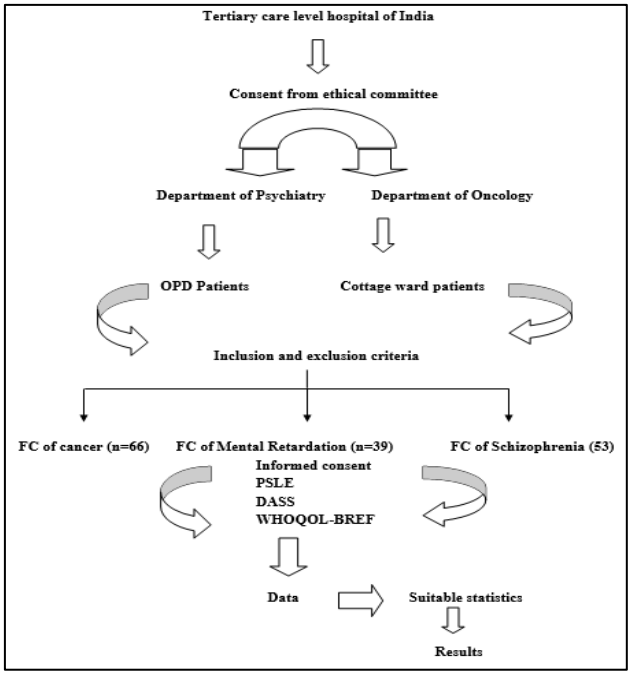

Figure 1: Flow chart of methodology.

Table 1: Scoring of DASS.

Outcome	Normal	Mild	Moderate	Severe	Extremely severe
Depression	0-9	10-13	14-20	21-27	28+
Anxiety	0-7	8-9	10-14	15-19	20+
Stress	0-14	15-18	19-25	26-33	34+

Observations

The study consist of 158 FC from three different disorders namely cancer, mental retardation and schizophrenia. These subjects were spouse, parents or any other family members.

Table 2 shows socio-demographic data of the FC.66 FC of cancer patients who were fulfilling the criteria were interviewed in detail out of which 50.9% were male and rest were female having mean age of 43.09±6.8 years. Most of the FC were employed 53.03%, while 27.3% FC were unemployed and rest were pensioner. 48.48% FC completed their higher education, 34.84% FC had primary education and remaining FC were uneducated. Most of the caregivers of cancer patients were spouse (48.48%), parents (21.21%) and other family members (30.30%). Out of 53 schizophrenia patients caregivers 79.24% were male and rest were female having mean age of 48.25±5.5 years. Mostly, FC were employed (45.28%), while 32.07% FC were unemployed and remaining were pensioner. 60.37% FC completed their higher education, 18.86% FC have primary education and rest FC were uneducated. Most of the caregivers of schizophrenia patients were spouse (58.49%), parents (13.20%) and other family members (28.30%).

The total 39 caregivers of mental retardation patients consists of 30.76% male and 69.23% females having mean age of 34.33±2.9 years. Mostly, subjects were employed (58.97%), 33.33% subjects were unemployed and 7.69% were pensioner. 56.41% subjects completed their higher education, while 25.64% subjects have primary education and 17.94% subjects were uneducated. Most of the caregivers of mental retardation patients were parents (94.87%) and other family members (5.12%).

Table 2: Socio demographic detail of family caregivers.

	Profile of care givers	Cancer (n=66)	Schizophrenia (n=53)	Mental Retardation (n=39)
Gender	Male	39 (50.90)	42 (79.24)	12 (30.76)
	Female	27 (40.90)	11 (20.75)	27 (69.23)
Age (Mean±SD)	In years	43.09±6.86	48.25±5.54	34±5
Education status	Uneducated	11 (16.67)	11 (20.75)	7 (17.94)
	Primary	23 (34.84)	10 (18.86)	10 (25.64)
	Higher	32 (48.48))	32 (60.377)	22 (56.41)
Employment status	Employed	35 (53.03)	24 (45.283)	23 (58.97)
	Unemployed	18 (27.3)	17 (32.07)	13 (33.33)
	Pensioner	13 (19.7)	12 (22.64)	3 (7.692)
Relationship with patients	Parents	14 (21.21)	7 (13.20)	37 (94.87)
	Spouse	32 (48.48)	31 (58.49)	0 (0.00)
	Other	20 (30.30)	15 (28.30)	2 (5.12)

*Figures in parenthesis shows the percentage.

Table 3: Presumptive stressful life events in family caregivers.

Variables	Subjects	Mean score	Std. deviation	S.E.M	F - Value	Level of significance
Total stressful life events	Cancer	7.00	1.52	0.18	9.86	0.000*
	M R	6.02	1.58	0.25		
	Schizophrenia	5.75	1.70	0.23		
Desirable life events	Cancer	0.51	0.74	0.09	0.62	0.53
	M R	0.66	0.73	0.11		
	Schizophrenia	0.52	0.63	0.08		
Undesirable life events	Cancer	5.31	1.30	0.16	17.36	0.000*
	M R	4.33	1.34	0.21		
	Schizophrenia	3.86	1.46	0.20		
Ambiguous life events	Cancer	1.16	0.97	0.11	1.66	0.19
	M R	1.02	0.81	0.12		
	Schizophrenia	1.35	0.81	0.11		
Mean stress score for total life events	Cancer	321.84	78.15	9.62	12.02	0.000*
	M R	269.28	79.77	12.77		
	Schizophrenia	253.26	85.03	11.16		
Mean stress score for desirable life events	Cancer	21.34	30.72	3.78	0.12	0.88
	M R	24.15	27.73	4.44		
	Schizophrenia	22.05	25.78	3.54		
Mean Stress score for undesirable life events	Cancer	265.12	72.56	8.93	14.13	0.000*
	M R	216.41	76.06	12.18		
	Schizophrenia	192.75	79.10	10.86		
Mean stress score for ambiguous life events	Cancer	35.37	30.40	3.74	1.52	0.22
	M R	28.71	23.50	3.76		
	Schizophrenia	38.45	23.74	3.26		

Table 3 depicts stressful life events in FC of cancer, MR and Schizophrenia patients assessed on PSLE. Mean of total stressful life events for cancer FC were 7±1.5, for MR 6.02±1.5 and for schizophrenia FC was 5.75±1.70. This difference was found to be statistically significant. Mean of total desirable life events for cancer FC were 0.51±0.74, for MR 0.66±0.73 and for schizophrenia FC was0.52±0.63. However this difference was not found to be statistically significant.

Mean of total undesirable life events for cancer FC were 5.31±1.3, for MR 4.33±1.34 and for schizophrenia FC was 3.86±1.46. This difference was also found to be statistically significant.

Mean of total ambiguous life events for cancer FC were 1.16±0.97, for MR 1.02±0.81 and for schizophrenia FC was 1.35±0.81. This difference was also not found to be statistically significant.

Mean stress score of total life events for cancer FC were 321.84±78.15, for MR 269.28±79.77 and for schizophrenia FC was 253.26±85.03. This difference was found to be statistically significant.

Mean stress score of desirable life events for cancer FC were 21.34±30.72, for MR 24.15±27.73 and for schizophrenia FC was 22.05±25.78. This difference was found to be statistically insignificant.

Mean stress score of undesirable life events for cancer FC were 265.12±72.56, for MR 216.41±76.06 and for schizophrenia FC was 192.75±79.10. This difference was also found to be statistically significant.

Mean stress score of ambiguous life events for cancer FC were 35.37±30.40, for MR 28.71±23.5 and for schizophrenia FC was 38.45±23.74. This difference was found to be statistically not significant.

Table 4 shows that on screening the Family caregivers on DASS scale it was found that among cancer FC 51.51% were having anxiety, 84.4% acknowledged being mentally stressed due to care giving, and 30.3% of the caregivers had clinical depression. The FC of MR 43.58% were having anxiety, 82.1% acknowledged being mentally stressed due to care giving, and 25.6% of the caregivers had clinical depression. While in FC of schizophrenia it was found that 32.07% were anxious, 77.35% of the caregivers had mental stress and 20.2% screened positive for depression. After using ANOVA within the groups it was found that there was no statistically significant difference among these groups.

As evident from the table 5, among the cancer FC having anxiety more than 50 % were having moderate anxiety, about 48 % had moderate stress and 50 % had moderate depression. Similarly among the MR FC more than 58 % were having moderate anxiety, about 46 % had mild stress and 54 % had moderate depression. In the schizophrenia patients screening positive for DASS about 58% were having moderate anxiety, about 51 % had moderate stress and 54 % had mild depression.

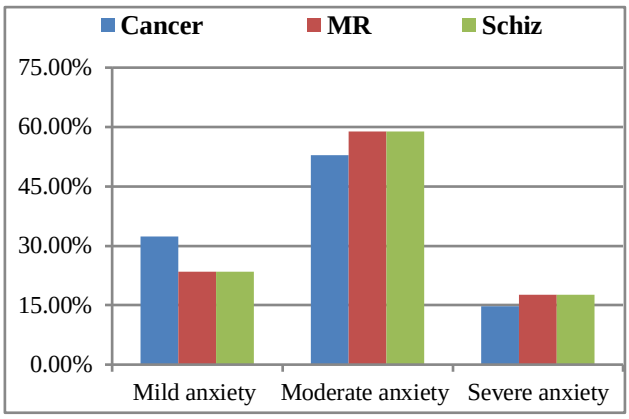

Figure 2: Severity of anxiety among FC according to DASS score.

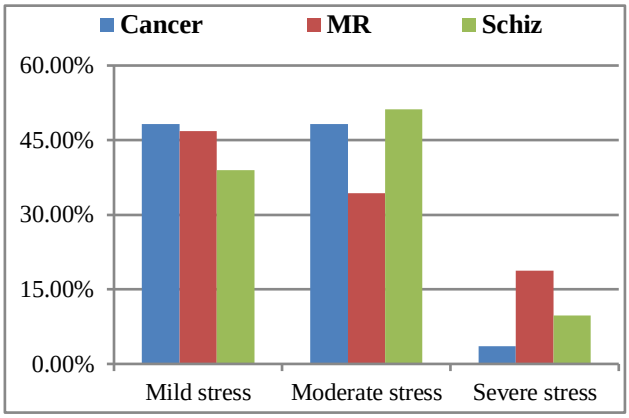

Figure 3: Severity of stress among FC according to DASS score.

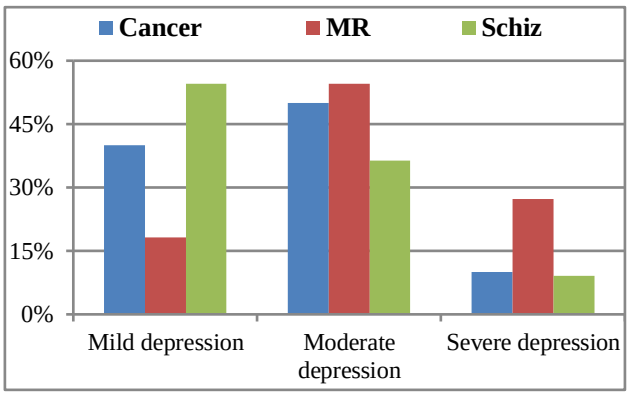

Figure 4: Severity of depression among FC according to DASS score.

Figure 2 shows the diagrammatic representation of severity of anxiety in family caregivers of cancer, mental retardation and schizophrenia on DASS scale. Most of the FC of all three groups had moderate anxiety. Figure 3 is the bar chart representation of severity of stress in

family caregivers of cancer, mental retardation and schizophrenia on DASS scale. Most of the FC of all three groups had mild or moderate stress.

Table 4: DASS score of FC of cancer, MR and schizophrenia patients.

Disorder	Anxiety		Stress		Depression	
	Yes	No	Yes	No	Yes	No
Cancer (n=66)	34 (51.51)	22 (48.49)	56 (84.4)	10 (15.6)	20 (30.3)	46 (69.7)
M R (n=39)	17 (43.58)	22 (56.42)	32 (82.1)	7 (17.9)	11 (25.6)	28 (74.4)
Schizophrenia (n=53)	17 (32.07)	36 (67.93)	41 (77.35)	12 (22.65)	11 (20.2)	42 (79.8)
Significance between the groups	0.307		0.455		0.304	

*Figures in parenthesis shows percentage.

Table 5: Severity of anxiety, stress and depression in FC according to DASS score.

Disorder	Anxiety			Stress			Depression		
	Mild	Moderate	Severe	Mild	Moderate	Severe	Mild	Moderate	Severe
Cancer (n=66)	32.35	52.94	14.7	48.21	48.21	3.6	40	50	10
M R (n=39)	23.52	58.82	17.64	46.87	34.37	18.75	18.18	54.54	27.27
Schizophrenia (n=53)	23.52	58.82	17.64	39.02	51.21	9.75	54.54	36.36	9.09

*figures in percentage

Table 6: WHO QOL score of FC of Cancer (n=66), MR (n=39) and Schizophrenia (n=53) patients (Anova).

		Mean	Standard deviation	Standard error	95% Confidence interval for mean
					Lower Bound - Upper Bound
Physical	Cancer	50.27	8.64	1.06	48.14-52.39
	MR	51.46	4.31	0.69	50.06-52.86
	Schizophrenia	47.84	5.21	0.71	46.40-49.27
	Total	49.75	6.81	0.54	48.67-50.82
Psychological	Cancer	47.91	11.01	1.35	45.20-50.62
	MR	49.46	4.89	0.78	47.88-51.05
	Schizophrenia	48.42	7.71	1.06	46.30-50.55
	Total	48.47	8.72	0.69	47.09-49.84
Social	Cancer	52.02	11.51	1.41	49.18-54.85
	MR	54.91	7.08	1.13	52.61-57.20
	Schizophrenia	59.43	7.13	0.97	57.46-61.39
	Total	55.22	9.70	0.77	53.69-56.74
Environmental	Cancer	47.77	7.63	0.93	45.89-49.65
	MR	46.23	4.71	0.75	44.70-47.76
	Schizophrenia	48.70	4.91	0.67	47.34-50.05
	Total	47.70	6.19	0.49	46.73-48.67

Figure 4 shows the diagrammatic representation of severity of depression in family caregivers of cancer, mental retardation and schizophrenia on DASS scale. Most of the FC of all three groups had moderate depression. However depression was found to be more severe in family caregivers of mental retardation.

Table 6 depicts that on screening the family caregivers on WHOQOL-Bref scale it was found that in cancer FC mean score in physical, psychological, social and environmental domain was 50.27, 47.91, 52.02 and 47.77 respectively. Similarly in FC of MR patients the mean score in physical, psychological, social and environmental domain was 51.46, 49.46, 54.91 and 46.23 respectively. While in schizophrenia FC mean score in these domains was 47.84, 48.42, 59.43 and 48.70 respectively.

It is evident from table 7 that difference in mean score of WHOQOL was statistically significant in physical and social domain depicting high impact on physical health and social life of these care givers.

DISCUSSION

This study was aimed to assess stressful life events in the family caregivers (FC) of cancer, mental retardation and schizophrenia patient, to assess and compare the level of anxiety, stress, and depression in them and to assess Quality of life in these caregivers. 66 FC of cancer patients, 39 FC of MR patients and 53 FC of Schizophrenia patients fulfilling the inclusion and exclusion criteria and giving informed consent were screened on PSLE, DASS, and WHO-QOL. Data so collected was subjected to suitable statistical analysis using SPSS-21. On PSLE Mean of total stressful life events for cancer FC was 7±1.5 which was higher than MR (6.02±1.5) and schizophrenia FC (5.75±1.70) and this difference was found to be statistically significant. Mean of total undesirable life events for cancer FC were 5.31±1.3, for MR 4.33±1.34 and for schizophrenia FC was 3.86±1.46.

Table 7: Analysis of Variance of WHO QOL score in FC of Cancer, MR and Schizophrenia patients (Anova).

Domain		Sum of squares	Df	Mean square	F	p
Physical	Between groups	325.22	2	162.61	3.61	0.029*
	Within groups	6973.67	155	44.99		
	Total	7298.90	157			
Psychological	Between groups	58.97	2	29.48	0.38	0.682
	Within groups	11897.77	155	76.76		
	Total	11956.75	157			
Social	Between groups	1620.54	2	810.27	9.53	0.000**
	Within groups	13168.92	155	84.96		
	Total	14789.46	157			
Environmental	Between groups	137.48	2	68.74	1.81	0.167
	Within groups	5886.30	155	37.97		
	Total	6023.78	157			

This difference was also found to be statistically significant. Similarly difference in mean stress score of total life events as well as for undesirable events on PSLE was also significantly higher in cancer patients. Haley et al, Coristine et al, also found higher level concerns about the future, coping with the situation, fear of loss, being alone, sole responsibility of children, or unfamiliar tasks at home are situational factors which may be seen as stressors influencing the quality of care given to patient.[29,30]

In this study 51.51% FC of cancer patients were having anxiety, 84.4% acknowledged being mentally stressed and 30.3% of the caregivers had clinical depression on DASS scale while the corresponding data in FC of MR was 43.58%, 82.1% and 25.6%.

In FC of schizophrenia these figures were 32.07%, 77.35% and 20.2%. No statistically significant difference was found within the groups on DASS scale. Despite having significantly lesser number of stressful life events in MR and Schizophrenia, similar prevalence of stress, anxiety and depressive symptoms indicates higher level of care giving burden in mentally ill patients in comparison to the physical illness.

WHO-QOL was found to be affected in every domain with significant difference in physical and social domain depicting high impact on physical health and social life of these care givers. With the advancement of medical science, although the life span of the patient has increased yet at the cost of the quality of the life. In this study, among the four domains of WHOQOL-Bref, mean satisfaction rating was found to be almost equal in physical and mental illness which implies social relationships of caregivers of both type of illness patients suffer similarly. Akbari M et al, in their study found that not meeting the needs of caregivers, burn out, high burden of care, high social stigma, low social support for care giver and low quality of life for care givers were among the most important challenges faced by care givers.[31]

CONCLUSION

Family caregiver of cancer patients have to face significantly higher number of stressful life events, yet the level of stress, anxiety and depressive symptoms are felt in approximately same amount in the care givers of mental illness patients. High level of stress and depression in family caregivers of mentally ill patients is

a call for urgent need of provision of professional care services such as half way homes, sheltered accommodation for not only treatment and rehabilitation of mentally ill persons but also to reduce the excessive care giving burden.

Quality of life of these care givers is also affected in each and every domain, physical and social domain being the most affected. Physician treating to chronic mentally ill persons should be vigilant for early identification of appearance of psychological symptoms in family caregivers as they are potential high risk group requiring psychological, social and sometimes medical intervention. Simultaneously attempts should be made towards psychoeducational programs and psychosocial support for families and care givers of patients with mental illness to destigmatise the current scenario.

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