

Psychological Distress and Quality of Life of the Care Givers of the Persons with Mental Disabilities

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Abstract

Since time immemorial, mental disorders have affected the lives of individuals all over the world. Their treatment, cure and care have been of concern for the patient themselves, and also their caregivers, society and government. Humans live in a family setup and when one falls ill, it is the family members who are automatically assigned to take care of the patient during his illness. They, as family members feel a lot of burden and stress in managing the individual diagnosed with the disorder. Also, it was found that social support and behavioural ways such as physical activities mediated the impact of chronic strain.

Keywords: Psychology, mental disabilities, distress, quality of life, disorder, caregivers, psychiatric care.

Introduction

Since time immemorial, mental disorders have affected the lives of individuals all over the world. Their treatment, cure and care have been of concern for the patient themselves, and also their caregivers, society and government. Humans live in a family setup and when one falls ill, it is the family members who are automatically assigned to take care of the patient during his illness. Additionally, as a result of de- institutionalization and the increasing shift of psychiatric care to the community, the role of family caregivers has gained importance (Kaushik and Bhatia, 2013). Hence, the responsibilities of the caregivers increase tremendously as they have to take care of the patient’s medical, financial and social needs along with their own personal needs.

They, as family members feel a lot of burden and stress in managing the individual diagnosed with the disorder. There have been various studies to see the caregiver’s burden and the resultant decrement in their resilience and quality of life (Marsh, Kersel, Havill, & Sleight, 1998; Burt et al, 2004; Saarni, 2010). Social support has been identified as possibly mediating the burden response (Brooks, Campsie, Symington, Beattie, & McKinlay 1987). Talsma (1995), in a cross-sectional study evaluated the theoretical model of resilience. It was suggested that chronic strain was a risk factor that had a detrimental effect on an individual’s resilience.

Also, it was found that social support and behavioural ways such as physical activities mediated the impact of chronic strain. In India, Gururaj, Math, Reddy, and Chandrashekhar's study (2008) highlighted that the family & economic burden along with psychological distress were significantly higher in people with schizophrenia as compared to other mental disorders. Kaushik and Bhatia (2013) conducted a study on the burden & distress and quality of life in spouses of patients with schizophrenia and bipolar disorder. The results indicated significant effects of gender and family type on spousal burden. The quality of life of spouses of people with mental illness proved to be somewhat lower than that of the general population.

These studies provide us with insight into the caregiver's issues, however, there aren't enough researches examining Quality of life of and Psychological Distress, or the Resilience among caregivers of individuals diagnosed with Mental Disabilities, such as schizophrenia, Bipolar Disorder or any other severe illness. Moreover, a combination comparing these two variables (QOL and Psychological Distress) together and how it has an impact on the caregivers has not been attempted. Thus, the present research was undertaken to analyze these aspects.

The Research Questions

The following research questions have come into sight...

- Do the Care givers of Persons with Mental Disability (PMD) have the Psychological Distress?
- If so, what is their level of Psychological Distress?
- Do the Care givers of PMD have the Quality of Life (QOL)?
- If so, what is their level of Quality of Life ?
- Whether Psychological Distress is influencing the Quality of Life for PMD?

Aim

The main aim of the present study is to find out the relationship between the level of Psychological Distress and Quality of Life among the care givers of PMD, with the following specific objectives.

Specific Objectives

- To understand the selected socio demographic profile of the care givers of the PMD.
- To measure the level of Psychological Distress & Quality of Life (QOL) of the PMD.
- To find out the relationship between the Psychological Distress & QOL of the PMD.

Research Design

The authors have used Descriptive Research design for the present study. An attempt has been made to describe the socio demographic profile of the care givers, to study the Psychological Distress, and the Quality of Life (QOL) of the care givers of PMD and the association between the above. Hence most suitable design would be Descriptive Research design.

Research Hypotheses

After having carefully reviewed various literatures the following research hypotheses have been formulated.

- Higher the Psychological Distress Lesser will be the QOL for the care givers of PMD.
- The care givers of Persons with MR have Low Psychological distress and High QOL than the care givers of Persons with MI.

Universe

All the Caregivers of Persons with Mental Illness (MI) and Mental Retardation (MR) who have registered themselves in "SUBITCHEM"- A Family Fellowship Programme run by M.S.Chellamuthu Trust and Research Foundation, A Psycho Social Rehabilitation Centre, Madurai. This initiative was started in the year 1999. So far 722 Care givers have registered and these people constitute as Universe for the present study.

Inclusion Conditions

- Care givers who have provided care for more than Two years for the ill.
- Both Male & Female

Exclusion Conditions

- Those who are not cooperating till the completion of Research study

Sampling

The Psychiatric Social Workers working at “SUBITCHEM”, have prepared a list of care givers from the universe by adopting the inclusion and Exclusion conditions. After words from the list, 60 care givers (30 for MI and 30 for MR) were selected randomly using Lottery method. Thus stratified random sampling technique was implemented for this study to draw the samples.

Tools for Data Collection

- To measure the level of Psychological Distress the 28 items General Health Questionnaire (GHQ-28) by Goldsberg, D.P. & Hillier, V.F (1979) was administered. The scale has 4 sub dimensions namely 1) Somatic Symptoms 2) Anxiety & Insomnia 3) Social Dysfunction 4) Severe Depression and Total Psychological Distress. It has high reliability (0.94) and Validity (0.97).
- To measure the Quality of Life(QOL) of the Care givers, for the PMD, the 26-item, World Health Organization Quality of Life Scale -

Brief Version (WHO-QOL BREF) which has four subscales namely, 1) Physical health, 2) Psychological health, 3) Social relationships, and 4) Environmental factors along with the Total QOL was administered. The scale has high reliability (0.89) and high Validity (0.94).

Methods of Data Collection

“SUBITCHEM”, The Family Fellowship meeting will be organized once in a month (i.e., all the 3rd Sundays), by M.S. Chellamuthu Trust and Research Foundation, Madurai. During that meeting, there will be an experience sharing by the caregivers and this will be moderated by the professionally trained Social workers and Psychiatrists. More inputs will be provided on Psycho Social Rehabilitation for the caregivers. Before starting the Fellowship meeting, the translated interview tools have been given to caregivers and required, relevant information have been obtained from them.

Socio Demographic Details

S.No	Factors	MI (30)		MR (30)	
		N	%	N	%
Age (CG)					
1	Below 30	4	13.3	3	10
	31-35	9	30	10	33.3
	36-40	10	33.3	11	36.7
	Above 41	7	23.4	6	20
Gender (CG)					
2	Male	15	50	15	50
	Female	15	50	15	50
Religion (CG)					
3	Hindu	18	60	17	56.7
	Muslim	2	6.7	4	13.3
	Christian	10	33.3	9	30
Type of Family (CG)					
4	Joint	11	36.7	10	33.3
	Nuclear	19	63.3	20	66.7
Place of Lining (CG)					
	Rural	17	56.7	14	46.7
	Urban	13	43.3	16	53.3

Monthly Income (CG)					
6	Below 3000	5	16.7	6	20
	3000 – 5000	9	30	8	26.7
	5000 – 7000	12	40	11	36.7
	7000 and above	4	13.3	5	16.6
Education (CG)					
7	Primary	6	20	5	16.7
	Secondary	9	30	10	33.3
	HSC	10	33.3	11	36.7
	College	5	16.7	4	13.3
Occupation (CG)					
8	Unskilled	11	36.7	10	33.3
	Semiskilled	13	43.3	15	50
	Skilled	6	20	5	16.7
Sex (Patient)					
9	Male	16	53.3	13	43.3
	Female	14	46.7	17	56.7
Age Patients					
10	Below 18	9	30	8	26.7
	19-25	12	40	10	33.3
	26-30	6	20	7	23.3
	Above 30	3	10	5	16.7
Duration of Illness					
	Below 5	8	26.7	6	20
	5 – 10	13	43.3	14	46.7
	10 – 15	9	30	10	33.3

It has been found that, just above one third of the Care Givers are in (31 to 35) and (36-40) years of age. Equal number of Male & Female Care Givers have been selected. Majority of Care Givers are Hindus (56.7%), from Nuclear Families (66.7%), from Urban areas (53.3%), Rs 5000 to Rs 7000 as their Monthly Income, Educated Higher Secondary

& above level, involving in Semi Skilled nature of work for their daily bread.

While discussing the profile of the persons with mental disabilities, it is evident that 56.7 per cent of them are Female persons with Mental Disabilities, form (26 & above) years of age, suffering with the illness for more than six years.

Results on the Level of Psychological Distress of the caregivers of PMD

S.No	Dimensions of Psychological Distress	MI	MR	't' Value	Statistical Results
1	Somatic Symptoms	60.57	49.88	11.52	P < 0.05 Sig
2	Anxiety & Insomnia	62.81	51.67	9.81	P < 0.05 Sig
3	Social Dysfunction	68.93	55.84	6.74	P < 0.05 Sig
4	Severe Depression	51.55	47.83	6.88	P < 0.05 Sig
5	Total Psychological Distress	62.98	51.76	7.71	P < 0.05 Sig

To measure the level of Psychological Distress for the Care Givers, the 28 items General Health Questionnaire (GHQ-28) by Goldsberg, D.P. & Hillier, V.F (1979) was administered. It was observed that the care givers of the persons with mental illness have more psychological distress (Mean % = 62.98) when compared to the care givers of persons with mental retardation (Mean % = 51.76).

Similar trend is also observed in all the dimensions namely somatic symptoms (60.57%), Anxiety & Insomnia (62.81%), Social dysfunction (68.93%), Severe depression (51.55%). The above mentioned differences are statistically significant since the 't' values are significant at 0.05 level.

Quality of Life Care givers of Persons with MI&MR

S.NO	Dimension of Quality of Life	MI (MEAN %)	MR (MEAN %)	Statistical result
1	Physical Health	47.46	51.65	't' = 6.44 P<0.05 Sig
2	Psychological Health	43.58	59.87	't' = 7.64 P<0.05 sig
3	Social Relationship	39.13	52.07	't' = 5.99 P<0.05 sig
4	Environmental	49.63	54.51	't' = 6.11 P<0.05 sig
5	Total QOL	46.91	55.29	't' = 4.84 P<0.05 sig

Quality of Life (QOL) of the Care givers, for the PMD, was measured with the help of the 26-item, World Health Organization Quality of Life Scale - Brief Version (WHO-QOL BREF). It has been found that the care givers for Persons with MR have more QOL (55.29 %) when compared to care givers for MI (46.91 %). Further the Care Givers of the Persons with M.R have scored high in Psychological Health, which indicates that they are Psychologically

more strong when compared to the other group of Care Givers. It is also evident that the Care Givers of Persons with M.I have scored very less in Social Relationship dimension when compared to the other type of Care Givers. This clearly indicates that still the Care Givers do face the problem of Stigma in the Society when they take care of the Mentally Ill persons. These difference are statistically significant, as the 't' values are significant at 0.05 level.

Association between Psychological Distress & QOL for the Care Givers of PMD

S.No	Dimensions of Psychological Distress	Total Quality of Life	Stat Result
1	Somatic Symptoms	'r' = - 0.678	P < 0.05 Sig
2	Anxiety & Insomnia	'r' = - 0.579	P < 0.05 Sig
3	Social Dysfunction	'r' = - 0.701	P < 0.05 Sig
4	Severe Depression	'r' = - 0.652	P < 0.05 Sig
	Total Psychological Distress	'r' = - 0.868	P < 0.05 Sig

It has been found that there exists a negative and significant association between the Psychological Distress and Quality of Life (QOL) for the Care givers of PMD ('r' = - 0.868, P < 0.05 Sig). Which means, when the sub dimensions scores of Psychological Distress like, Somatic Symptoms, Anxiety & Insomnia, Social Dysfunction, Severe Depression, and the Total Psychological Distress increases the level of Quality of Life will decrease. Thus the formulated Hypothesis is verified.

Suggestions

Based on the findings of the present study, it is suggested that proper and periodic Psycho Education could be provided to the Care Givers of Persons with Mental disabilities. Further the World Health Organization's (WHO) 10 Life Skills Training Programme could be implemented to the Care Givers of Persons with Mental disabilities. Finally, to reduce the Psychological Distress for the Care Givers, the importance of Yoga and Meditation could be initiated.

Conclusion

To summarize, it can be stated, this study has added to the understanding of the level of Psychological Distress and Quality of Life in caregivers of different chronic mental disorders and the relationship between psychological distress and Quality of Life of caregivers of Persons with Mental Disabilities.

Implications

When chronic patients are taken care of in a formal set up like hospitals, clinics, nursing homes or NGO's, along with the consultation for medical purposes and welfare of the patient, focus may also be put on improving the quality of life and resilience

of caregivers so that their coping with the continuing psychological stress can be handled in a better manner. Although, it was not analyzed, most of the participants (caregivers) expressed the view that they experienced financial constraints in looking after their wards, and that they did not get leisure time for themselves. In order to provide aid to the caregivers, certain entertainment and learning skills can be imparted. These would include providing social support and interaction via recreational activities such as a picnic, etc and at the same time teaching skills to the caregivers to improve their monetary funds.

The basic idea, may be thought of now is a rehabilitation program not just for the patients, but the caregivers as well so that their quality of life is improved and consequently their coping skills and resilience becomes better.

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