

Comparative study of family burden and quality of life of close caretakers of patients of schizophrenia and drug addiction

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Schizophrenia and drug addiction, in its most form is severe and usually long lasting, causing maximum disability. The burden of care on the family members of patients with schizophrenia and drug addiction become much more compared to other mental disorders. The present study was mainly aimed at understanding that Schizophrenia and drug addiction can also affect the quality of life and the health of the family members. For this 60 schizophrenic patients and 60 drug addict patients diagnosed as per ICD-10 criteria with at least two years duration of illness were identified in District Mental Health Programme, Kurukshetra. The close care takers of family members of these patients were studied by administering the scale of family burden (Family Burden Schedule) and Quality of life (WHOQOL-BREF). The result of study have revealed that longer the duration of illness greater the overall burden. The illness of patients also significantly effects the quality of life of close care taking members of the family. The study has shed significant light on family and social consequences of schizophrenia and drug addiction.

Keywords: schizophrenia, drug addiction, family burden and quality of life

The psychiatric illnesses are commonly prevalent in all age groups, sexes, races, cultures and geographical areas. They take a chronic course and result in serious consequences. It is estimated that over 500 million people may be suffering from some kind of mental disorder or impairment (WHO, 1996). According to world (mental) health report (2001), 24 million people world wide suffer from schizophrenia.

Schizophrenia is a severe psychiatric disorder, which is chronic and disabling. It is one of the most serious mental illness with about 1 in 100 people developing the disorder over a life time. The estimated cost of schizophrenia in term of treatment, men hour lost and other expenses is tremendous. The burden on the family is heavy and both the patients and their relatives are exposed to stigma. Schizophrenia is thus a major public health issue.

Substance abuse and other addictive behaviour disorders are among the most prevalent mental health disorders in most of the societies all over the world. Significant health and social costs are attributed to excessive involvement with alcohol, nicotine, illicit, drugs, prescription drugs, industrial solvents and impulse control problems. Current substance abuse or dependence is present in 11% of the US population and nearly 27% have met criteria during their life time (Kessler et al., 1994). Alcohol is the most widely used intoxicating substance. Illicit drug use has increased in recent decades and prevalence rates of individual substances fluctuate over time. Nearly 36% of US population over the age 12, has used on illicit drug in their life time (SAMHSA, 1995). Illicit drugs present particular medical risks because the content of any drug obtained on the street is specify. These drugs are at risk for HIV, hepatitis infections, vein deterioration and endocarditis (Peterson et al., 1998)."

From the beginning of the community mental health movement in the era of 1960's there has been a shift from traditional custodial care to community care. Majority of the psychiatric patients and addicts live in community with their families. Treating such patients at home although decrease the load on the hospital, reduces financial strains, helps early recovery and prevents chronic handicap but it increase

the burden on the family and the community. Family burden as per the Goldberg and Huxley (1980) is defined as the adverse effect the patient has upon his family. Pai & Kapur (1981) state burden as difficulties felt by the family of a psychiatric and addictive patient.

Schizophrenia and addictive behaviour disorders, and the disabilities associated with them, place a burden on the care givers and the family as a whole in the areas such as financial, social and emotional. The care-givers are likely to experience prolonged depression, guilt, shame or anger over the patients or at themselves.

Schizophrenia, and addictive disorders along with placing a burden on the family also affects the quality of life and health of the caregivers. Quality of life has been defined by the WHO as an individuals perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards and concern.

Caregivers of schizophrenic and addictive patients experienced significant family burden and their quality of life is also disrupted. This observation prompted us to measure the family burden and quality of life of caregivers of schizophrenic and addictive patients in our clinical setting.

Objectives of the study

- To assess the quality of life of caretakers of schizophrenic and addictive patients.
- To assess the family burden on caretakers of schizophrenic and addictive patients.
- To compare the burden perceived by the caretakers of schizophrenic and addictive patients based on duration of illness.
- To compare the quality of life of the caretakers of schizophrenic and addictive patients based on duration of illness.

Method

The present study was carried out in the district mental health programme and drug de-addiction centre, Kurukshetra.

Participants

Sixty schizophrenic and 60 drug addictive patients along with their

caretakers attending the district mental health programme and visiting drug de-addiction centre, Kurukshetra comprised the study sample. The subjects were caretakers of schizophrenics drug addicts who accompanied the patients to the mental health clinic and de-addiction centre for treatment purpose.

Diagnosis

The patients were diagnosed as per DSM-IV criteria for schizophrenia and addictive behaviour disorders. Only those schizophrenics and addictive patients with duration of illness 6 month or more were included in the study.

Research Design

A comparative research design was adopted for the study to compare the family burden and quality of life between two groups of caretakers of schizophrenic and addictive patients based on duration of illness.

First group consisted of shorter duration of schizophrenic and addictive illness (<2 yrs) whereas the second group consisted of the relatives of longer duration of schizophrenic and addictive illness (>2yrs).

Information regarding socio-demographic variables was collected. Family burden was assessed by using the schedule for the assessment of family burden (SAFB, Pai and Kapur, 1981). Quality of the life was assessed by using scale for the WHOQOL-BREF (WHO, 1996). The total scores of family burden and quality of life in the caretakers of schizophrenic patients were compared on the basis of shorter (<2yrs) and longer (>2yrs) duration of schizophrenia. The

data obtained was statistically analyzed by Y test.

Instruments

Schedule for the Assessment of Family Burden (SAFB, Pai and Kapur, 1981): This is a semistructured interview schedule to assess the burden on families of psychiatric patients living in the community. Reliability of the interview schedule was about 90% for 20 items and between 87 and 89% for the other 4. Regarding validity the reported coefficient of correlation is 0.72 (d.f. = 1).

The objective burden was calculated by adding up the scores. The maximum objective score that could be scored was 48. A score of 0-24 was assigned moderate burden and 25-48 severe burden respectively.

Whoqol-bref: The WHOQOL-BREF of a generic and Trans-cultural Quality of Life (QOL) assessment instrument developed by WHO (WHOQOL-100). It is a 26 item scale with 5-point likert responses having four subscales measuring physical health, psychological well-being, social relationship and satisfaction with the environment.

The four subscale scores are calculated by summing up the scores of the corresponding items in each subscale. The overall score is the summation of all subscale scores and two global items scores. The relatives were made to understand the purpose of the study. They were encourage to answer the questions of the questionnaire honestly with out any bias. The data so obtained was subjected to statistical analysis.

Results and Discussion

Table I and II shows the following results of family burden of caretakers.

Table I: Comparison of Family Burden in Caretakers Based in Duration of Illness of Schizophrenic Patients

S. Variables N.	Group - I Short Duration of Illness (<2years)		Group - II Longer Duration of Illness (>2years)		t-values	P-value
	Mean	SD	Mean	SD		
1 Financial Burden	3.27	1.96	5.53	1.99	4.38	P<0.05 Significant
2 Effect on Family Routine	3.77	2.09	3.43	2.50	0.565	P>0.05 NS
3 Effect on Family Leisure	2.63	1.67	3.27	2.53	1.142	P>0.05 NS
4 Effect on Family Interaction	2.53	2.03	2.8	2.22	0.486	P>0.05 NS
5 Effect on Physical Health of other Family members	1.13	0.97	1.53	1.07	1.498	P>0.05 NS
6 Effect on Mental Health of other Family members	1.7	0.87	2	0.87	1.321	P>0.05 NS
Total	15.03	6.13	18.57	8.09	1.88	P>0.05 NS

Table -II Comparison of Family Burden in Caretakers Based in Duration of Illness of Drug-addicts

S Variables N	Group-I Shorter duration of illness		Group -II Longer duration of illness		t-value	P-value
	M	SD	M	SD		
1. Financial Burden	5.96	3.44	7.86	3.72	2.010	0.05 Siq
2. Effect on family Routine	4.34	.85	5.04	1.24	2.37	0.05 Siq
3. Effect on family leisure	5.17	1.36	6.19	1.53	2.47	0.05 Siq
4. Effect on family interaction	0.58	.68	1.04	.86	2.11	0.05 Siq
5. Effect on Physical Health of other family members	5.65	1.20	6.38	1.39	1.97	NS
6. Effect on Mental Health of other family members	1.37	.72	1.57	.59	.99	NS
Total	23.07	8.28	28.08	9.33	-2.20	0.05

The overall family burden mean scores of caretakers of longer (18.75 ± 8.09) and shorter (15.03 ± 6.13) duration of schizophrenic patients

do not show statistical significance. Financial Burden mean scores were statistically more significant among caretakers of schizophrenic

patients with longer duration of illness (mean 5.33 ± 1.99) as compared to that of shorter duration of illness (mean 3.27 ± 1.96). Findings show that longer the duration of illness, greater is the burden experienced. However, mean scores of family burden on various items like effect on family routine, effect on family leisure, effect on family interaction, effect on physical health of other family members, effect on mental health of other family members and subjective burden were higher for the caretakers of longer duration of schizophrenic illness as compared to that of shorter duration of illness, but result were not statistically significant.

The overall family burden mean scores of caretakers of longer

(28.08 ± 9.33) and shorter (23.07 ± 8.28) duration of drug-addictive patients show statistical significance ($t = -2.20$ $p < .05$). Table shows that mean scores of four areas of family burden i.e. financial burden, family routine, family leisure and family interaction among caretakers of addictive patients with longer duration of illness are statistically significant as compared to the mean score of their counterparts. However, the mean scores on physical health and mental health of other family members are statistically insignificant.

Table-III and IV shows the following results of quality of life of caretakers.

Table III: Comparison of Quality of Life in Caretakers Based in Duration of Illness of Schizophrenic Patients

S N	Variables	Group I Short Duration of Illness (<2years)		Group - II Longer Duration of Illness (>2years)		t- values	P- value
		Mean	SD	Mean	SD		
1	Physical Health	5.96	3.47	7.86	3.72	2.010	P<0.05 Significant
2	Psychological Well being	6.8	3.31	6.3	4.45	0.487	P>0.05 NS
3	Social relationship	3.43	3.42	1.93	2.79	1.842	P>0.05 NS
4	Satisfaction with the environment	10.23	4.71	10.2	5.58	0.022	P>0.05 NS
	Total	24.83	12.85	23.36	14.04	0.417	P>0.05 NS

Table IV: Comparison of Quality of Life in Caretakers Based in Duration of Illness of Drug-addicts

S N	Variables	Group-I Shorter duration of illness		Group II Longer duration of illness		t-value	H
		M	SD	M	SD		
1.	Physical Health	5.76	1.17	6.10	1.42	.90	NS
2.	Psychological well being	6.09	1.23	5.83"	1.40	.62	NS
3.	Social relationship	4.34	.83	5.0^	1.23	2.36	0.05 Siq
4.	Satisfaction with the environment	4.50	2.17	6.19	2.02	2.60	0.05 Siq
	Total	20.69	5.4	23.15	6.07	1.66	

The overall quality of life between the caretakers of the shorter (24.83 ± 12.85) and longer (23.36 ± 14.64) duration of schizophrenic patients does not show statistically significance. The quality of life scores (mean 7.89 ± 3.72) in the physical health related item were greater in the caretakers of schizophrenic patients having longer duration of illness as compared to the shorter duration of illness (mean; 5.97 ± 3.47). The results are statistically significant. However, the scores of quality of life were higher in various items like psychological well-being, social relationship, satisfaction with the environment, for the caretakers of schizophrenic patients as compared to shorter duration of illness.

The nature of schizophrenic illness being chronic and disabling impacts burden on the caretakers of schizophrenic patients and it also effect the quality of life. The overall quality of life behaviour the caretakers of the shorter (20.69 ± 5.4) and longer (23.15 ± 6.07) duration of drug addictive patients don't show statistically significant difference. However, the differences in score of two areas of quality of life i.e. social relationship and satisfaction with the environment are statistically significant at .05 level. Like schizophrenia, drug addictive behaviour disorders also exert family burden on the caretakers and also distort is close their quality of life, With regard to the comparative evaluation of effects schizophrenia and addictive illness on the family burden and quality of life of close caretakers, the results obtained in the present study (table-I-VI) depict that longevity of addictive behaviour is more burdensome on the caretakers as compared to the caretakers of schizophrenic, patents whereas

longevity of schizophrenia exerts more distorting effect on the quality of life of caretakers than that of addictive problems.

The main findings of this study are that caretakers of both the groups of shorter and longer duration of schizophrenic and addictive patients experienced burden in the areas assessed which include financial, effect on family routine, effect on family leisure, effect on family interaction, effect on physical health of other family members and effect on mental health of other family members. These findings were supported by the study of Gautam et al. (1984) and Saldanha et al. (2002) who found that the caretakers of schizophrenic patients experienced burden in all the above areas.

The burden experienced in the financial areas was significant high among the caretakers of longer duration of illness (>2yrs) as compared to caretakers of shorter duration of illness (<2yrs) of schizophrenic as well as addictive patients. This is evident that due to longer duration of illness, specifically if the patient is bread earner is the family than the income incurred by the patient, stops. On the other hand, the addictive patients not only stop their personal earnings, they also waste the family asserts in making the availability of addictive drugs. Similarly, the caregivers due to the chronicity of the illness have to spend a part of their income on them, may also stop earning/lose their job because of care giving process for a longer time. Moreover, similarly due to choronicity cost of maintains of treatment, frequent hospitalization etc. increased the financial burden. Mors et al. (1992) reported that longer duration of schizophrenic illness placed more burden in the family.

Quality of life scores in our study were statistically significant in the caretakers of schizophrenic patients with longer duration of illness. The findings can be explained on the basis that with chronicity caretakers, while providing care to the patients, neglect their own physical health in various areas like activities of daily living, dependence on medical substances, fatigue, pain and discomfort, sleep and rest and work capacity. Our findings are supported by the study of Lucas (1998) and Sartorius (1992).

In our study the quality of life score were higher in various items like psychological well-being, social relationship, satisfaction with the environment in the caretakers of schizophrenic patients with shorter duration of illness. In a shorter duration of illness, the caretakers are prepared to face the difficulties related to the schizophrenic illness. The result/mean scores are lower when duration of illness increases, one of the reason may be that with the passage of time the caretakers may become used to face the situations as a results of chronicity. Similarly are the findings of Lucas (1998) and Orley et al. (1998). On the other hands, the addictive patients themselves are more sufferers from their addictive problems, they are socially rejected by the closely related persons. With longevity of drug addiction, they usually keep on lying in isolation without causing any disturbance to the family.

Conclusion

The findings have a bearing for the psychological management of schizophrenic and addictive patients, implicating that considerations should be given to the financial aspect of schizophrenia as well as addictive patients with a longer duration of illness. Schizophrenic and addictive patients may be involved in occupational therapy so that they become less dependent on their families and they learn to be

gainfully employed in some activity. For the improvement of quality of life of the caretakers may be provided supportive therapy, family therapy so that they may cope well and their quality of life may improve. The personal interview with addicted patient revealed the lack of community reinforcement to them. The present study recommends that the addictive patients also require the sympathy. Whereas, the community usually handle them punitively. Hence they should also be considered as patents and be managed by combining the element of positive community reinforced with other means of treatment.

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