

Burden of Care and Social Behaviour Problem of Patients with Schizophrenia

Zahiruddin Othman, Mohd. Razali Salleh

ABSTRACT

Objective: To assess the relationship between levels of burden on primary caregivers and social behaviour problem of patients with schizophrenia.

Design: Cross-sectional study.

Materials and Methods: The study involved forty five patients attending Psychiatry Clinic. The level of burden on primary caregivers was assessed using Burden on Family Interview Schedule (BFS) and the social behaviour problem of patients with schizophrenia was assessed using Social Behaviour Schedule (SBS).

Results: Employment status and monthly household income of primary caregivers were significantly correlated with amount of burden. Caregivers experienced enormous amount of both subjective and objective burden. Financial burden was the greatest objective burden affecting at least one third of the caregivers. Amount of burden experienced by primary caregivers was significantly correlated with social behaviour problem of patients particularly hostility, over activity, restlessness, and destructive behaviour.

Conclusion: The levels of burden on caregivers are high with employment status and monthly household income of caregivers are predictive of higher levels of burden.

KEY WORDS

schizophrenia, caregivers, burden, social behaviour problem

INTRODUCTION

Burden on caregiver is a complex issue involving many factors. Living with the patient, patient behaviour, demographic characteristics, and socioeconomic status have all been associated with varying amount of burden^{1,2,3}.

Burden on caregiver includes financial responsibilities, missed work, disturbance of domestic routines, constraints on social and leisure activities, and reduced attention to other family members^{4,5}. The financial strain due to medical costs and economic dependency of patients are considerable⁶. Family members may give up work outside the home to provide care for the person with mental illness. Siblings who must cope with the problem may need therapy, which increases medical bills⁷. Family members may become ill and/or indebted and that divorce may result from the chronic financial and emotional strain⁸.

Behavioral problems of the patient such as frequent and intense arguments, withdrawal, bizarre behavior that is disturbing to neighbours, and threatened or actual harm to self or others contribute to the experience of burden. Also iden-

tified as sources of burden are a variety of household complaints about patient behavior, such as being noisy at night, failing to adhere to a regular time schedule, being generally uncooperative, refusing to do household chores, being verbally abusive, and making unreasonable demands⁹.

The caregiver frequently suffers from severe mental and emotional drain, feels utterly defeated, and has feelings of anxiety, resentment, and anger, with stress being cumulative over time^{10,11,12}.

Despite the universal recognition of the distress experienced by the caregivers, the specific social behavioural problems related to a greater level of family burden are not well understood and may be different in local setting. The present study was therefore, conducted in order to examine the relationship between severity of burden on primary caregivers of patient with schizophrenia and social behaviour problem of patient.

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Department of Psychiatry, School of Medical Sciences, Universiti Sains Malaysia, Health Campus
16150 Kubang Kerian, Kelantan, Malaysia

Correspondence to: Zahiruddin Othman
(e-mail: zahir@kb.usm.my)

Table 1. Sociodemographic characteristics of patients and primary caregivers

		Patients n (%)	Primary caregivers n (%)
Gender	Male	31 (68.9)	17 (37.8)
	Female	14 (31.1)	28 (62.2)
Mean age \pm SD	Male	29.1 \pm 8.5	50.65 \pm 16.7
	Female	34.5 \pm 11.9	52.43 \pm 10.9
Marital status	Single	29 (64.4)	3 (6.7)
	Married	10 (22.2)	34 (75.6)
	Separated	1 (2.2)	1 (2.2)
	Divorce	5 (11.1)	2 (4.4)
	Widow	0 (0)	5 (11.1)
Educational level	Nil	0 (0)	8 (17.8)
	Primary	4 (8.9)	14 (31.1)
	Secondary	36 (80.0)	14 (31.1)
	Tertiary	5 (11.1)	9 (20.0)
Income per month	Nil	33 (73.3)	0 (0)
	< MYR 500	7 (15.6)	16 (35.6)
	MYR 500- 1000	3 (6.7)	15 (33.3)
	MYR 1000- 3000	2 (4.4)	12 (26.7)
	> MYR 3000	0 (0)	2 (4.4)
Employment status	Unemployed	32 (71.1)	0 (0)
	Odd job	5 (11.1)	9 (20.0)
	Housewife	3 (6.7)	11 (24.4)
	Government servant	3 (6.7)	8 (17.8)
	Self-employed	1 (2.2)	9 (20.0)
	Student	1 (2.2)	0 (0)
	Pensioner	0 (0)	8 (17.8)
Duration of treatment (month)	6-12	5 (11.1)	
	12-24	3 (6.7)	
	24-60	11 (24.4)	—
	> 60	26 (57.8)	
Relation to patient	Parents		33 (73.3)
	Spouse		9 (20.0)
	Siblings	—	2 (4.4)
	Others		1 (2.2)
Duration of staying together (months)	6-12		1 (2.2)
	12-24		3 (6.7)
	24-60	—	2 (4.4)
	> 60		39 (86.7)

METHODOLOGY

Forty five subjects were recruited from outpatient psychiatric clinics, Universiti Sains Malaysia. This study was approved by the Human Research and Ethics committee, School of Medical Sciences, Health Campus, Universiti Sains Malaysia.

Inclusion criteria for patients were a diagnosis of schizophrenia according to International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10) criteria, aged 18-65, living in Kelantan with relative for a minimum period of 6 months prior to interview,

and had not been hospitalized during the last month.

A primary caregiver is defined as someone living in the same household, feel most responsible for patient, having most face-to-face contact with primary care taking role. Inclusion criteria for primary caregivers were aged at least 18 years old and absence of disabling physical or psychiatric disorders. All relatives and patients gave their informed consent before participation in the study.

Amount of burden on primary caregivers of patient with schizophrenia was measured with Burden on Family Interview Schedule (BFS)¹³. Social behaviour problem of patient was measured with the Social and Behaviour Schedule (SBS)¹⁴.

Table 2. The number of caregivers scoring 2 (severe burden) on the Burden on Family Interview Schedule (BFS)

Category of burden	n (%)
Objective burden	
<i>Financial burden</i>	
Loss of patient's income	7 (15.6)
Loss of income of other family members	3 (6.7)
Expenses of patient's illness	16 (35.6)
Expenses due to other necessary changes in arrangement	7 (15.6)
Loan taken or saving spent	0 (0)
Any other planned activity needing finance postponed	0 (0)
<i>Disruption of routine family activities</i>	
Patient not attending work, school, etc	0 (0)
Patient unable to help in household duties	6 (13.3)
Disruption of activities of other members of the family	7 (15.6)
Patient's behaviour disrupting activities	11 (24.4)
Neglect of the rest of the family due to patient's illness	1 (2.2)
<i>Disruption of family leisure time</i>	
Stopping of normal recreational activities	3 (6.7)
Patient's illness using up another person's holiday and leisure time	12 (26.7)
Lack of participation by patient in leisure activity	1 (2.2)
Planned leisure activity abandoned	3 (6.7)
<i>Disruption of family interaction</i>	
Ill effect on general family atmosphere	12 (26.7)
Other members arguing over the patient	1 (2.2)
Reduction or cessation of interaction with friends and neighbours	1 (2.2)
Family becoming secluded or withdrawn	1 (2.2)
Any other effect on family and neighbourhood relationship	2 (4.4)
<i>Effect on physical health of others</i>	
Physical illness in family members	1 (2.2)
Any other adverse effect on others	1 (2.2)
<i>Effect on mental health of others</i>	
Any member seeking professional help for psychological illness	0 (0)
Any members becoming depressed, weepy and irritable	5 (11.1)
Subjective burden	18 (40.0)

All statistical analyses were performed using the commercially available software package, SPSS version 11.5. Correlation between sociodemographic characteristics of patients/primary caregivers with amount of burden as measured by total BFS score was assessed using ANOVA. $P < 0.05$ was regarded as significant. Pearson's correlation coefficients were used to assess correlation of social behaviour problem with amount of burden. All data were analyzed using the Mann-Whitney test.

RESULTS

Table 1 shows sociodemographic characteristics of patients and primary caregivers. The mean age of patients was 29 and 34 years for males and females respectively. About 71% were unemployed though 80% of them received secondary education. Most of patients were chronic schizo-

phrenia in which 58% had been on treatment for more than 5 years. None of patient's gender ($p = 0.949$), marital status ($p = 0.528$), educational level ($p = 0.052$), monthly income ($p = 0.108$), employment status ($p = 0.182$) and duration of treatment ($p = 0.469$) was significantly correlated with amount of burden as measured by total BFS score.

The mean age of primary caregivers was 51 and 52 years for males and females respectively. Two thirds of them had household income less than MYR 1,000 per month. About three quarter of caregivers was parents and 88% had been living together for more than 5 years. Employment status ($p = 0.001$) and household income ($p = 0.014$) are significantly correlated with amount of burden. Otherwise, primary caregiver's gender ($p = 0.758$), educational level ($p = 0.250$), marital status ($p = 0.626$), relation to patient ($p = 0.573$) and duration of living together ($p = 0.912$) were not significantly correlated.

Table 2 shows the number of caregivers scoring 2 or severe burden on the BFS. The commonest severe burden experienced by primary caregivers was expenses of patient's

Table 3. The frequency of social behaviour problem (scoring 2 or more on Burden on Family Interview Schedule) and correlation with amount of burden

SBS Items	Numbers of Caregivers reporting Heavy Burden in BFS n (%)	Correlation with total objective burden score in BFS
		Pearson's <i>r</i>
1. Little spontaneous communication	10 (22)	0.495
2. Incoherence of speech	9 (20)	0.438
3. Odd or inappropriate conversation	13 (29)	0.586
4. Inappropriate social mixing	7 (16)	0.549
5. Hostility	18 (40)	0.748
6. Demanding attention	2 (4)	0.293
7. Suicidal ideas or behaviour	0 (0)	0.000
8. Panic attacks and phobias	0 (0)	-0.023
9. Overactivity and restlessness	12 (27)	0.700
10. Laughing or talking to self	19 (42)	0.671
11. Acting out bizarre ideas	8 (18)	0.327
12. Posturing and mannerisms	2 (4)	0.343
13. Socially unacceptable habits or manners	2 (4)	0.466
14. Destructive behaviour	15 (33)	0.684
15. Depression	0 (0)	0.013
16. Inappropriate sexual behaviour	0 (0)	0.047
17. Poor self-care	13 (29)	0.563
18. Slowness	2 (4)	0.333
19. Underactivity	10 (22)	0.381
20. Poor attention span	3 (7)	0.532
21. Other behaviour	2 (4)	0.054
Number of social behavior problem		0.881
Total SBS score		0.863

Table 4. The correlation between patient's social behaviour problem and total objective burden subcategory of burden

Category of burden	Total SBS score	No of problem behaviour
	Pearson's <i>r</i>	Pearson's <i>r</i>
Objective burden		
1. Financial burden	0.652	0.677
2. Disruption of routine family activities	0.774	0.782
3. Disruption of family leisure time	0.812	0.789
4. Disruption of family interaction	0.624	0.672
5. Effect on physical health of others	0.045	0.029
6. Effect on mental health of others	0.660	0.686
Subjective burden	0.806	0.809

t's illness (35.6%) which is an item under financial burden. This was followed by patient's illness using up another person's holiday and leisure time (26.7%), an item under disruption of family leisure time, and ill effect on general family atmosphere (26.7%) which is an item under disruption family interaction. Severe subjective burden is reported by 40% of primary caregivers.

Table 3 shows the frequency of social behaviour problem (scoring 2 or more on BFS) and correlation with amount of burden. The 5 most frequent social behaviour problems were laughing or talking to self (42%), hostility (40%), violence or threats (33%), odd or inappropriate conversation (29%) and poor self-care (29%). The first 4 of

these behaviour problems are the direct product of active psychosis, whereas the fifth usually results from chronicity.

Correlation of social behaviour problem with amount of burden is as shown in Table 4. Strong correlation with amount of burden was seen with number of social behaviour problem and total SBS score. Moderate correlation ($0.500 < r < 0.800$) was seen in 8 SBS items. In descending order these were hostility, overactivity and restlessness, destructive behaviour, laughing or talking to self, odd or inappropriate conversation, poor self care, inappropriate social mixing and poor attention span. Correlations of other items were weak ($0.200 < r < 0.500$) or negligible ($r < 0.200$).

All the categories of objective burden had moderate to

strong correlations with total SBS score and number of problem behaviour except effect on physical health of others, $r = 0.045$ and $r = 0.029$ respectively. Subjective burden showed strong correlations with social behavior problem.

DISCUSSIONS

The extent of burden

The greatest objective burden affecting one third of the caregivers were expenses on patient's illness, which is categorised under financial burden. About three thirds of patients were unemployed (71%) and had no income (73%). The caregivers were mainly from low socioeconomic groups. Two thirds of them had a monthly household income of less than MYR 1,000. The transportation, registration and medication fees were the recurring expenses for each visit to the outpatient clinic.

Three BFS items, namely patient's illness using up another person's holiday and leisure time, ill effect on general family atmosphere and patient's behaviour disrupting activities affected about one quarter of caregivers. Previous study reported that the last 2 items were significantly associated with neurotic symptoms in caregivers¹⁵.

Severe subjective burden is reported by 40% of primary caregivers which is comparable to a local study that reported 35% in neurotic and 20% in normal caregivers wherein 31% of patients receiving treatment more than 5 years compared to this study 58%¹⁵. Another study reported 40% of caregivers suffer from depression with younger age group and lower levels of education predictive of higher levels of caregivers' depressive symptoms¹⁶.

Most of the caregivers (62%) were women with mean age of 52 years, which is similar to the previous study by Madianos and colleague¹⁵. However, almost three quarter (73%) of the caregivers was parents and most of the caregivers had been taking care of patients for more than 5 years as reported by others¹⁷. More chronic illness and greater proportion of elderly mothers probably explains the greater percentage of caregivers experiencing severe burden. A study found that mothers have the highest levels of burden followed by fathers and other caregivers¹⁸.

Sociodemographic characteristics and levels of burden

Findings on the relationship between sociodemographic characteristics of patients and caregivers and level of burden on caregivers in the present study are consistent with previous studies conducted elsewhere in Malaysia^{15,19}. None of the patient's sociodemographic characteristics had significant association with amount of burden.

Results on the employment status and monthly household income in this study support a previous findings by Martyns-Yellowe in 1992²⁰ which found that a high burden score to be associated with rural setting and poorer economic circumstances of the family. Rural families in the study were poorer economically and were therefore more likely to feel the expense of treatment, and transportation for follow-up treatment, as a burden. In contrast to the study conducted by Salleh¹⁵ on 210 rural primary care-

givers of Malay schizophrenic, family income was not significantly correlated with the amount of burden.

No age-specific effect of either the patient's age or the caregiver's age on the amount of burden of caregiving was found in this study as reported in the study by²¹. This could be due to the selection of patients in a younger age group excluding the elderly and organic patients. Grad & Sainsbury²² reported increasing burden with age probably because of the association with diagnoses of organic psychosis. Hoenig & Hamilton²³ found that the younger the patient the more the total objective burden whereas increasing age of the patient was associated with increasing subjective burden. Probably the age effect is present only in patients older than 50 years and therefore not found in this sample of patients.

Social behaviour problem and levels of burden

In the present study, both the number of problem behaviour and total SBS score had strong correlation with total objective burden as well as subjective burden. Two-thirds of the relatives are at times faced with behavioural disturbances, e.g. nuisances, threats, and even physical aggression²⁴. Previous studies^{15,25} had shown the kind of behaviour relatives found most distressing and difficult to cope with was that directed towards them or were the product of active psychosis such as hostility, violence, overactivity and restlessness and acting out bizarre ideas. On the contrary, Gopinath and Chaturvedi²⁶ noted that behaviours related to activity and self-care were perceived to be most distressful, and not aggressive or psychotic behaviour. However, in their study, most of the caregivers were males (61%) and from urban background (66%).

CONCLUSION

In conclusion, levels of burden on caregivers are high with employment status and monthly household income of caregivers are predictive of higher levels of burden. It is important for community based maintenance treatment of schizophrenia to incorporate of psychoeducation²⁷, focused group discussions, family support, counseling and telecommunications into regular treatment of schizophrenia is needed in order to alleviate the burden on caregivers.

Further study should focus on an intervention study of burden before and after psychoeducation on coping strategies of caregivers. Such programs should focus not only on coping with hostility and destructive behaviour, but also with the needs of relatives regarding leisure activities.

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