

# Burden of Care in Schizophrenia: Implication of Psychopathology of the Illness

Zahiruddin O, Salleh MR

Department of Psychiatry

School of Medical Sciences, Universiti Sains Malaysia, 16150 Kubang Kerian, Kelantan, Malaysia

**Abstract:** The recent trend towards community psychiatry appears to have shifted much of the burden of care of the chronically mentally ill from the institutions to the family. The objective of this study was to assess the implication of psychopathology in forty five schizophrenic patients on burden experience by their primary caregivers. Patients' psychopathology was assessed using Positive and Negative Syndrome Scale (PANSS) and the burden on caregivers was measured using Burden on Family Interview Schedule (BFS). The prevalence of burden was extensive with 40% reported severe subjective burden. The greatest objective burden was treatment expenses affecting 35.6% of primary caregivers. Schizophrenic patients' psychopathology (particularly delusion, hostility and hallucinatory behaviour) was found to be significantly correlated with the amount of burden experienced by primary caregivers. Grandiosity and stereotyped thinking were the least burdensome symptoms imposed on the caregivers.

**Key words:** Schizophrenia, psychopathology, family burden, caregivers

Malaysian Journal of Psychiatry September 2005, Vol. 13, No. 2

## Introduction

The Malaysian government started decentralizing psychiatric services in the early 1960s. Deinstitutionalization policy tries to unite patients with their families as a means of providing community care. This policy catapults the patients' relatives into a caregiving role for which they are untrained and unprepared and from which they have been systematically excluded in the past (1).

The severity of patients' symptoms is the most important predictors of burden especially difficult behaviour and disability (2, 3, 4). However, there is no clear-cut consensus from available studies regarding the symptoms that the relatives find most stressful.

Burden can be further classified into objective and subjective factors (5). Objective burden consisted of the concrete factors seen to disrupt family life and subdivided according to specific effects on the family household, the health of other family members, family routine, and in particular abnormal behaviour likely to cause distress. Subjective burden refers to

the subjective experience or psychological or emotional impact (i.e., feeling worried or strained) of caring for someone with a mental illness.

The findings from burden studies on social activities and interpersonal life consistently show that these are restricted or disrupted (6, 7). Social isolation is also a prominent feature of caring for the long-term mentally ill and often social contacts are either limited or substantially reduced (8). Caregivers' emotional responses also vary from negative feelings of resentment, feeling overloaded and trapped (9) to positive responses of gratification (10). A primary concern includes the detrimental effect on caregivers' psychological health, and is a consistent finding in a number of studies on burden (11).

The objective of this study was to assess the implication of psychopathology in schizophrenic patients on burden experience by their primary caregivers.

## Material and Methods

The cross-sectional study was conducted at the outpatient clinic, Department of Psychiatry of University Science of Malaysia. This study was approved by the Human Research and Ethics committee, School of

### Correspondence:

Dr Zahiruddin Othman, Department of Psychiatry, School of Medical Sciences, Universiti Sains Malaysia, 16150 Kubang Kerian, Kelantan, Malaysia. E-mail: zahir@kb.usm.my

Table 1: Sociodemographic characteristics of patients and primary caregivers.

	Patients Value (%)	Primary caregivers Value (%)
<b>Gender</b>		
Female	31 (68.9)	17 (37.8)
Male	14 (31.1)	28 (62.2)
<b>Mean age <math>\rho</math> SD</b>		
Male	29.06 $\rho$ 8.52	50.65 $\rho$ 16.74
Female	34.50 $\rho$ 11.95	52.43 $\rho$ 10.87
<b>Marital status</b>		
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	-	5 (11.1)
<b>Educational level</b>		
Nil	-	8 (17.8)
Primary	4 (8.9)	14 (31.1)
Secondary	36 (80.0)	14 (31.1)
Tertiary	5 (11.1)	9 (20.0)
<b>Income per month</b>		
Nil	33 (73.3)	-
< 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	-	2 (4.4)

Malaysia. This study was approved by the Human Research and Ethics committee, School of Medical Sciences, Health Campus, Universiti Sains Malaysia.

A total of 45 patients who were accompanied by their key relatives in the outpatient clinic were recruited into the study if they fulfilled the criteria mentioned below. All relatives and patients gave their informed consent before participating in the study. Patients had to satisfy the following criteria:

- (i) Aged 18 to 65 years old.
- (ii) Absence of hospitalization during the last month.
- (iii) Living within the Kelantan state with a relative for a minimum period of 6 months before the interview.
- (iv) A diagnosis of schizophrenia according to ICD-10.

Relatives had to satisfy these criteria:

- (i) Aged at least 18 years old.
- (ii) They are the primary caregiver of patient who is defined as someone living in the same household; feel most responsible for patient, having most face-to-face contact and primary care taking role.
- (iii) Absence of disabling physical or psychiatric disorder or drug abuse.

Positive and Negative Syndrome Scale (12) was used to measure psychopathology in the schizophrenic patients. Burden on caregivers was measured whereas using Burden on Family Interview Schedule (13).

#### Statistical Analysis

Data entry and analysis were carried out using SPSS for Windows, version 10.0. Patient and caregiver

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

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

characteristics were expressed using descriptive statistic and frequency.

Correlation between patient's psychopathology and burden of caregiver was examined by means of

Pearson's correlation coefficients. The degree of association/correlation was regard as 'strong' when  $0.8 < r < 1.0$ , 'moderate' when  $0.5 < r < 0.8$ , 'weak' when  $0.2 < r < 0.5$  and 'negligible' when  $0.0 < r < 0.2$ . The statistical significance was taken at the 5% level or

Table 3: The correlation between patient's psychopathology (PANSS) and total objective burden (BFS) score.

PANSS items	Pearson' r (n=45)
Positive scale	0.789
1.P1 (delusion)	0.649
2.P2 (conceptual disorganization)	0.460
3.P3 (hallucinatory behavior)	0.639
4.P4 (excitement)	0.499
5.P5 (grandiosity)	0.221
6.P6 (suspiciousness / persecution)	0.590
7.P7 (hostility)	0.648
Negative scale	0.523
1.N1 (blunted affect)	0.511
2.N2 (emotional withdrawal)	0.443
3.N3 (poor rapport)	0.515
4.N4 (passive social withdrawal)	0.363
5.N5 (difficulty with abstract thinking)	0.385
6.N6 (lack of spontaneity)	0.356
7.N7 (stereotyped thinking)	0.148
General scale	0.476
<b>Total PANSS</b>	<b>0.626</b>

less ( $p < 0.05$ ). Bonferroni multiple comparison test was done for categorical variables having  $p < 0.05$  in order to look for difference between groups.

## Results

The sociodemographic characteristics of patients and primary caregivers.

The sociodemographic characteristics of patients and primary caregiver are summarized in Table 1.

Table 2 shows the number and percentage of caregivers scoring 2 (severe burden) on the Burden on Family Interview Schedule (BFS). The four commonest severe burden faced by primary caregivers were expenses of patient's illness (35.6%), patient's illness using up another person's holiday and leisure time (26.7%), ill effect on general family atmosphere (26.7%) and patient's behaviour disrupting activities (24.4%). 40% of primary caregivers reported severe subjective burden.

Table 3 shows positive scale ( $r=0.789$ ,  $p=0.01$ ) had the highest correlation. It is followed by total PANSS ( $r=0.626$ ,  $p=0.001$ ), general psychopathology scale ( $r=0.523$ ,  $p=0.01$ ) and negative scale ( $r=0.476$ ,  $p=0.01$ ). Among the individual items, only 6 items had moderate correlation ( $0.500 < r < 0.800$ ) with the amount of burden i.e. delusions ( $r=0.649$ ,  $p=0.01$ ), hostility ( $r=0.648$ ,  $p=0.01$ ), hallucinatory behaviour ( $r=0.639$ ,  $p=0.01$ ), suspiciousness / persecution ( $r=0.590$ ,  $p=0.001$ ), poor rapport ( $r=0.515$ ,  $p=0.01$ ) and blunted affect ( $r=0.511$ ,  $p=0.01$ ). The rest of the items had weak ( $0.200 < r < 0.500$ ) or no significant correlation ( $r < 0.200$ ).

Table 4 shows the positive scale had moderate correlation ( $0.500 < r < 0.800$ ) with disruption of routine family activities ( $r=0.778$ ,  $p=0.01$ ), disruption of family interaction ( $r=0.680$ ,  $p=0.01$ ), disruption of family leisure time ( $r=0.624$ ,  $p=0.01$ ) and financial burden ( $r=0.571$ ,  $p=0.01$ ). As for negative scale, only disruption of family leisure time ( $r=0.504$ ,  $p=0.01$ ) had moderate correlation. None of the category of burden

Table 4: The correlation between BFS category of burden with PANSS positive and negative subscales

Category of burden	Positive subscale	Negative subscale
	Pearson's r (n=45)	Pearson's r (n=45)
<b>Objective burden</b>		
1. Financial burden	0.571	0.394
2. Disruption of routine family activities	0.778	0.496
3. Disruption of family leisure time	0.624	0.504
4. Disruption of family interaction	0.680	0.172
5. Effect on physical health of others	0.122	-0.030
6. Effect on mental health of others	0.480	0.352
<b>Subjective burden</b>		

had strong correlation with either positive or negative scale. Subjective burden had moderate correlation with positive scale ( $r=0.791$ ,  $p=0.01$ ) but only weak correlation with negative scale ( $r=0.495$ ,  $p=0.01$ ).

## Discussion

Previous study had revealed that current symptomatology showed the strongest relationship with caregiving and caregivers' distress (14, 15). In this study, the positive scale had the highest correlation. This was followed by total PANSS, general psychopathology scale and negative scale. The positive scale had moderate correlation with 4 categories of objective burden, namely disruption of routine family activities, disruption of family interaction, disruption of family leisure time and financial burden, whereas only disruption of family leisure time had moderate correlation with the negative scale. None of the other category of objective burden had strong correlation with either positive or negative scale. Similarly, the subjective burden had moderate correlation with positive scale but only weak correlation with negative scale. Consistent with previous studies (15, 16), not only positive symptoms (delusions, hostility, hallucinatory behaviour and suspiciousness / persecution) had stronger correlation than negative symptoms (poor rapport and blunted affect), but they also caused a wider disruption across the family functioning, both objectively and subjectively. In contrast, other studies (17, 18, 19) reported caregivers who perceived patients as incapable of altering their

negative symptoms behaviours and meeting certain role obligations may assume extra responsibilities, leading to a higher level of burden.

The fact that only those patients accompanied by relative were recruited into the study has a propensity to elevate the scoring of the instruments. Many of these patients were recruited into the study around the time of the hospital admission, which often represented a phase of acute decompensation. The initial symptoms, which include irritability and agitation, eventually progressed to open hostility and anger, and the accompanying behaviour was frequently assaultive and explosive. Violence presumably remits as these acute symptoms improve (20). Thus, we cannot infer that the relatively high levels of burden reported in this study will generalise to periods of symptom remission. It is also possible the relatives that frequently accompany patient to clinic differ from those who are not. Studies (14, 21) had reported that relatives in regular contact with the patient's mental health professional reported more caregiving strains than those not in contacts. There are three possible explanations for this. First, these relatives belong to a subgroup that experiences caregiving as more burdensome than other relatives. As a consequence, they themselves tend to seek or maintain contact with the patient's mental health professional or this professional maintains contact with them. Second, contact with mental health professionals may influence the way relatives interact with the patients themselves. They may, more than

relatives not in contact, see themselves as co-therapists, perhaps even encouraged by clinicians to take that particular role, but nevertheless more often burdened with the task of supervising and urging the patient. Third, the fact of seeing a doctor may itself imply a crisis in the patient's health, a deterioration of symptomatology that increases caregiver distress (21).

In conclusion, the prevalence of burden was extensive with 40% reported severe subjective burden. The greatest objective burden experienced by the primary caregivers was treatment expenses affecting 35.6%. Caregivers in this study also reported that positive symptoms were more burdensome than the negative symptoms. Community psychiatric services may need to pay close attention to caregivers, particularly patient employment, financial and psychological support. Future research with a larger sample of patients recruited not only from the clinic but also from the community is needed to confirm present findings.

## References

1. Lefley HP. Family Caregiving in Mental Illness. In: Family Caregiver Application Series, Volume 7. Thousand Oaks, California: Sage publishers, 1996.
2. Ohaeri JU. Caregiver Burden and Psychotic Patients' Perception of Social Support in a Nigerian Setting. Soc Psychiatry Psychiatr Epidemiol 2001; 36: 86-89.
3. Jiska ED, Wolthaus MA, Peter MAL, *et al.* Caregiver Burden in Recent Onset Schizophrenia and Spectrum Disorders: The Influence of Symptoms and Personality Traits. J Nerv Ment Dis 2002; 190: 241-247.
4. Wittmund B, Wilms HU, Mory C, Angermeyer MC. Depressive Disorders in Spouses of Mentally Ill Patients. Soc Psychiatry Psychiatr Epidemiol 2002; 37: 177-182.
5. Hoenig J, Hamilton MW. The Schizophrenic Patient in the Community and his Effect on the Household. Int J Soc Psychiatry 1966; 12: 165-76.
6. Fadden G, Bebbington P, Kuipers L. Caring and its Burdens: A Study of Relatives of Depressed Patients. Br J Psychiatry 1987; 150: 660-7.
7. Mc Creadie RG, Wiles DH, Moore JW, Grant M, Crocket GT, Livingston MG, *et al.* The Scottish First Episode Schizophrenia Study: IV. Psychiatric and Social Impact on Relatives. Br J Psychiatry 1987; 150: 340-4.
8. Anderson CM, Reiss DN, Hogarty GE. Schizophrenia and the family: A Practitioner's Guide to Psychoeducation and Management. New York: Guildford Press, 1986.
9. Thompson EH, Doll W. The Burden of Families Coping with the Mentally Ill: An Invisible Crisis. Fam Relat: J Appl Fam Child Stud 1982; 35:379-88.
10. Bulger MW, Wandersman A, Goldman CK. Burdens and Gratifications of Caregiving: Appraisal of Parental Care of Adults with Schizophrenia. Am J Orthopsychiatry 1993; 63: 255-65.
11. Perring C, Twigg J, Atkin K. Families Caring for People Diagnosed as Mentally ill: The Literature Re-examined. London: HMSO, 1990.
12. Kay SR, Fiszbein A, Opler LA. The Positive and Negative Syndrome Scale (PANSS) for Schizophrenia. Schizophr Bull 1987; 16: 261-276.
13. Pai S, Kapur RL. The Burden of the Family of a Psychiatric Patient: Development of an Interview Schedule. Br J Psychiatry 1981; 138: 332-335.
14. Schene AH, van Wijngaarden B, Koeter MWJ. Family Caregiving in Schizophrenia: Domains and Distress. Schizophr Bull. 1998; 24(4): 609-618.
15. Franz M, Ehlers F, Quist T, Gallhofer B. Caring for Schizophrenic Patients in the Family: Burden of Care Related to Psychopathology and Behaviour. Schizophr Res 2000; 41(1): 167.
16. Salleh MR. The Burden of Care of Schizophrenia in Malay Families. Acta Psychiatr Scand. 1994; 89: 180-185.
17. Gopinath PS, Chaturvedi SK. Distressing Behaviour of Schizophrenics at Home. Acta Psychiatr Scand. 1992; 86: 185-188.
18. Provencher HL & Mueser KT. Positive and

- Negative Symptom Behaviours and Caregiver Burden in the Relatives of Persons with Schizophrenia. *Schizophr Res* 1997; 26: 71-80.
19. Blanchard JJ, Sayers SL, Collins LM, Bellack AS. Affectivity in the Problem-solving Interactions of Schizophrenia Patients and their Family Members. *Schizophr Res* 2004; 69:105–117
  20. Carlson GA, Goodwin FK. The Stages of Mania: A longitudinal Analysis of the Manic Episode. *Arch of Gen Psychiatr* 1973; 28: 221-228.
  21. Winefield HR, Harvey E J. Determinants of Psychological Distress in Relatives of People with Chronic Schizophrenia. *Schizophr Bull* 1993; 19(3): 619-625.