

BURDEN AND COPING IN CAREGIVERS OF PERSONS WITH SCHIZOPHRENIA

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ABSTRACT

Caring for a family member with schizophrenia is an enduring stressor and causes considerable amount of burden. The aim of the present study was to examine burden and coping in parents and spouses of persons with schizophrenia. The sample comprised of 24 parents and 24 spouses. Patients were assessed on the Global Assessment Scale (GAS), and caregivers were assessed on the Burden Assessment Schedule (BAS) and the Coping Checklist (CCL). Spouses reported greater emotional burden. Parents used more of denial as a coping strategy, while spouses used more of negative distraction strategies. On stepwise regression analysis, patient's age, educational level, and level of functioning and caregiver's use of denial as a coping strategy emerged as significant predictors of caregiver burden. The study highlights the fact that family intervention programs need to address the specific concerns of caregivers.

Keywords: burden, coping, schizophrenia, family caregiver

Families are an integral part of the care system for persons with a chronic mental illness, such as schizophrenia (Shankar & Menon, 1993). The demands of being involved in the care of a seriously mentally ill relative have both an emotional and a practical impact on the caregiver (Chakrabarti et al., 1995; Provencher, 1996). The costs that families incur in terms of economic hardships, social isolation and psychological strain, are referred to as family burden (Grad & Sainsbury, 1968; Pai & Kapur, 1981; Schene et al., 1998). Hoening and Hamilton (1966) attempted to distinguish between objective and subjective burden. The former includes the effects of the illness on finances and routine of the family, while the latter is defined as the extent to which family members are affected by objective burden.

Several patient and caregiver variables have been found to contribute to family burden. Greater

burden is associated with patients who are male (Gautam & Nijhawan, 1984; Martyns-Yellowe, 1992), younger in age (Martyns-Yellowe, 1992; Roychoudhuri et al., 1995) and who have poorer levels of functioning (Salleh, 1994; Winefield & Harvey, 1993). Caregiver characteristics associated with burden have received comparatively less attention. Women take on a large part of caregiving responsibilities (Jenkins & Schumacher, 1999), and caregivers who are younger and more educated experience greater burden (Gopinath & Chaturvedi, 1992).

Caregiving is a chronic stressor and different coping methods are used to handle such a situation. The use of coping strategies such as avoidance, denial and resignation is linked to greater burden (Budd et al., 1998; Hinrichsen & Lieberman, 1999; Scazufca & Kuipers, 1999; Sekharan et al, 2001). Utilization of social support

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and a sense of mastery over the situation are associated with lower level of burden and distress (Noh & Turner, 1987; Postasznik & Nelson, 1984). Greater use of problem solving coping and less use of denial is a predictor of wellbeing in family caregivers (Rammohan et al., 2002).

The relationship of the primary caregiver to the patient may also mediate the experience of burden. Several researchers have documented the concerns experienced by parent caregivers such as the patient's difficulty in achieving normative life-span goals e.g., finding a job, getting married and raising children (Pickett, et al., 1994; St. Onge & Lavoie, 1997). An additional concern for parents is who will take over the caregiving role after them (Hatfield & Lefley, 2000; Lefley, 1987). Spouse caregivers experience difficulty in terms of having to balance multiple roles, raising children, and financial burden, particularly when the illness strikes the primary wage earner (Mannion, 1996; Noh & Avison, 1988). However, not many studies have examined the coping strategies used by parents and spouses in relation to burden. Parents and spouses form the majority of the caregiver group in India. A comparison of burden experienced and coping strategies adopted by these two groups can help plan intervention programs that address their specific needs.

The aims of this study were 1) to examine differences in burden and coping styles across parents and spouses of patients with schizophrenia, and 2) to determine the extent to which patient and caregiver characteristics as well as coping styles of caregivers predict burden.

MATERIAL AND METHOD

Sample: The study was carried out on caregivers of patients diagnosed with schizophrenia, attending the outpatient Department of Psychiatry, NIMHANS, Bangalore. Patients fulfilling the ICD-10 diagnostic criteria for schizophrenia, with a duration of illness of at least 2 years, and who were on maintenance medication and regular follow up for at least 6 months, were included. Patients with co-morbid psychiatric conditions,

organic syndromes, mental retardation and substance dependence were excluded. Caregivers who were above 21 years of age, and living with the patient for at least one year prior to the interview, were included in the study. Caregivers with chronic physical illness and a history of past/current psychiatric consultation were excluded. Data was collected over a period of 4 months, during which time 60 caregivers met the inclusion and exclusion criteria and participated in the study. Of the 60 caregivers assessed, 12 were siblings of the index patient and data on them was excluded from further analysis. This paper presents data on 48 caregivers, of whom 24 were parents and 24 were spouses.

Tools: 1. A data sheet was used for recording sociodemographic details of the patient, duration of illness and duration of treatment, sociodemographic data of the caregiver, relationship to the patient and duration of care.

2. Global Assessment Scale (GAS, Endicott et al., 1976). This is a single rating scale that assesses the patient's level of functioning. This was rated independently by the caregiver as well as the investigator. Inter-rater reliability was 0.84. Both ratings were averaged to give a composite GAS rating.

3. Burden Assessment Schedule (BAS, Thara et al., 1998). This is a 40 item scale, which measures seven different areas of burden. Each item is rated on a 3-point scale. The scores range from 40 to 120, with higher scores indicating greater burden. Internal consistency for the full scale as measured by the alpha coefficient is 0.81. Criterion validity was computed against the Interview Schedule of Pai and Kapur (1981).

4. Coping Checklist (Rao et al., 1989). This is a 70-item scale, in a Yes/No format. It covers a wide range of cognitive, behavioral and emotional responses that are used to handle stress. There are seven subscales: problem solving, denial, positive distraction, negative distraction, acceptance, religion/faith and social support seeking. The test-retest reliability for a one-month period is 0.74 and the internal consistency for the full scale is 0.86.

Statistical Analysis: Complete data was available for all the measures and coded for computer analysis. Stepwise multiple regression analysis was conducted with burden as the dependent variable. The ratio of independent variables to participants was large and raised the possibility of a spurious inflation of multiple correlations. Data reduction was, therefore carried out using the method suggested by Levitt *et al.*, (1990) in the following manner. The dependent variables were divided into three sets: 1) patient characteristics (age, sex, education, occupational status, marital status, duration of the illness and composite GAS score), 2) caregiver characteristics (age, sex, education, occupational status, marital status, duration of care and relationship to the index patient), and 3) the 7 coping subscales. The unique contribution of each predictor set to variance in burden was assessed. Variables that yielded statistically significant parameter estimates on the dependent measure, *i.e.*, burden, were retained for further analysis. In the final regression equation, patient's age, education and GAS score, caregiver's education, relationship to the index patient and the coping subscale of denial were entered as the predictor variables.

RESULTS

Sociodemographic data

a) **Patients:** There were equal number of male and female patients in the parent group, while in the spouse caregiver group, there were more female patients. Patients in the parent group were younger in age and were less educated than patients in the spouse group. Of the 24 patients in the parent group, 13 were employed, whereas in the spouse caregiver group, 11 were employed. Of the 24 patients in the parent caregiver group, 18 were unmarried, and 6 were married, but had been abandoned by their spouses. Patients in the parent caregiver group had a shorter mean duration of illness. There was no significant difference in level of functioning, as indicated by the GAS scores, between both groups of patients.

TABLE 1
SAMPLE CHARACTERISTICS OF THE PATIENT AND CAREGIVER GROUPS

Variables	Parents (N=24)	Spouses (N=24)	t value
Patient			
Sex			
Male	12	7	2.18+
Female	12	17	
Mean age	29.29(±6.75)	43.04(±7.71)	6.57**
Mean education (in years)	9.96(±3.70)	6.46(±4.65)	2.88**
Occupation			
Employed	13	11	-
Unemployed	11	13	-
Marital Status			
Married	0	24	-
Unmarried	18	0	-
Separated/ Divorced	6	0	-
Mean duration of illness	6.9(±4.40)	12.25(±6.76)	3.25**
Mean duration of Treatment	5.63(±4.24)	11.17(±5.94)	3.72**
GAS score	68.75(±10.43)	71.98(±8.18)	1.19
Caregiver			
Sex			
Male	5	17	12.08**
female	19	7	
Mean age	54.4(±7.96)	47.29(±8.07)	2.92**
Mean education (in years)	5.88(±4.59)	7.50(±4.97)	1.17**
Mean duration of care (in years)	6.21(±3.20)	11.79(±6.93)	3.53**

+ = chi square test; df=1; *p<0.05, **p<0.01

b) **Caregivers:** In the parent group, there were more female caregivers, with 19 being mothers. In the spouse group, there were more male caregivers, with 17 being husbands. The parent caregivers were older than spouse caregivers. Commensurate with the duration of illness, the parent group had a shorter duration of care than the spouse caregivers. The mean duration of care for the spouse group was less than the mean duration of marriage of 22.68 years (±7.76). This indicates that onset of illness for patients in the spouse caregiver group was more than 10 years after their marriage. Almost all caregivers (N=47) were employed, and majority belonged to the lower and middle income groups (Table 1).

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TABLE 2
BURDEN SCORES OF PARENT & SPOUSE CAREGIVERS

Burden subscales	Parents (N=24)		Spouses (N=24)		t value
	Mean	SD	Mean	SD	
Financial Burden	8.87	2.45	10.29	2.61	1.94
Caregiver Occupation	7.45	1.10	6.79	1.32	1.90
Patient Behaviour	8.83	1.34	8.88	1.65	0.09
Social Relations	9.37	1.50	9.12	1.15	0.65
Caregiver Health	10.67	2.24	9.42	2.22	1.94
Family Relations	7.00	1.53	7.33	1.61	0.74
Emotional Burden	13.29	2.49	17.88	2.68	6.14**
Total Burden	65.50	8.61	70.00	8.74	1.80

**p<0.01

TABLE 3
COPING STRATEGIES USED BY PARENT AND SPOUSE CAREGIVERS

Coping Checklist subscales	Parents (N=24)		Spouses (N=24)		t value
	Mean	SD	Mean	SD	
Problem Solving	2.67	1.81	2.75	1.87	0.16
Distraction (positive)	1.83	1.43	1.70	1.12	0.34
Distraction (negative)	0.33	0.70	1.00	1.22	2.33*
Acceptance	5.29	1.73	5.29	1.12	0.00
Religion/Faith	3.42	1.59	3.21	1.53	0.71
Denial	3.75	1.92	2.58	1.69	2.24*
Social Support	1.71	1.49	1.46	1.56	0.57

*p<0.05

Burden in Parents and Spouses: The scores on the BAS indicate that both groups of caregivers experienced moderately high levels of burden. Emotional burden was significantly higher in spouses (Table 2).

Coping Strategies used by Parents and Spouses There was a significant difference between the two groups of caregivers on two of the coping strategies adopted, i.e., distraction-negative and denial. Parents used more of denial and spouses used more of negative distraction as coping strategies (Table 3).

Predictors of Burden: In the stepwise regression analysis, patient's age, education and GAS score and use of denial as a coping strategy by the

caregiver emerged as significant predictors, accounting for 72% of the variance in burden (Table 4).

DISCUSSION

This paper examined the differences in the experience of burden and coping styles between spouse and parent caregivers, and the role of patient and caregiver demographic variables, patient's level of functioning, and coping strategies of caregivers in contributing to burden.

The concept of family burden is often a 'gendered' notion, with the lion's share of primary caregiving being provided by female relatives (Jenkins & Schumacher, 1999; St. Onge & Lavoie, 1997). In the present study, this is true for the parent caregiver group, where most of the caregivers were women. However, in the spouse caregiver group, there were more men, in the caregiving role. While 6 of the 24 patients in the parent group had been abandoned by their spouses, 17 of the female patients in the spouse group had an intact marriage. This is probably because in the latter group, the onset of illness was almost 10 years after the marriage, allowing the marital dyad to have stabilized. The patients were also able to perform adequate role functioning in terms of carrying out their routine household chores and taking care of children. The presence of children may have been another protective factor in the marriage (Thara & Srinivasan, 1997).

Burden was experienced by both parents and spouses in their role as caregivers of persons with mental illness. Spouses reported greater emotional burden. This is an important finding and suggests that while the experience of objective burden may be similar for both parents and spouses, they differ in their experience of subjective burden. The BAS contains items that tap areas of emotional burden specific to spouses, such as the effect of the illness on the patient's ability to share responsibilities, sexual relations and the overall quality of the marital relationship. Intervention programs should address the specific needs of spouses. This can help to lower levels of distress in the spouse caregiver, as well as lead

TABLE 4
PREDICTORS OF BURDEN IN CAREGIVERS

Variables	R Square	Adjusted R Square	Std.β Coefficients	t value
Education of patient	0.38	0.36	-0.32	-3.46**
Use of Denial	0.59	0.58	0.46	5.60**
Age of patient	0.72	0.70	0.42	4.56**
GAS Score of patient	0.75	0.72	-0.18	-2.22*

F=31.72**, *p<0.05, **p<0.01

to a more benign course of illness for mentally ill persons in committed relationships (Mannion *et al.*, 1994).

Significant differences between the two groups of caregivers were found on two of the subscales of the coping checklist. Parent caregivers were found to use denial as a coping strategy more than spouses. Greater use of denial by the parent group suggests that it is harder for them to accept the reality of their child's illness. This can result in delay in seeking treatment or poor compliance with treatment. Intervention programs for parent caregivers, therefore, need to focus on enhancing acceptance of both illness and resulting disability and develop realistic expectations regarding outcome for the patient. Spouses used more of negative distraction strategies when compared to the parent group. Negative distraction strategies such as use of alcohol and drugs are reported more often in males. A predominance of male caregivers in the spouse group could have influenced the scores on this subscale. The results suggest that male caregivers need to be specifically targeted in intervention programs to teach them more adaptive ways of handling stress.

Age, educational level and level of functioning of the patient, combined with the use of denial as a coping strategy by caregivers, contributed to the experience of burden. Caregiving for older patients resulted in greater burden. This is in contrast to the findings of Martyns-Yellowe (1992) and Roychoudhuri *et al.*, (1995). As patients and caregivers grow older, concern as to who will take over the caregiving role is an important

question in the minds of most caregivers (Hatfield & Lefley, 2000; Lefley, 1987). Alternative residential facilities such as long stay homes is a need expressed and required by most aging caregivers (Gopinath & Rao, 1994).

Lower educational level of the patient contributed to greater caregiver burden. Education is linked to employment opportunities. Low literacy level in these patients resulted in their getting poorly paid menial jobs. This is a group of caregivers from a predominantly lower socioeconomic background and financial difficulties were a major concern for them. The results indicate that patients with low education levels will benefit from psychosocial rehabilitation programs that emphasize acquisition of work-related skills and income generation.

Despite the patients in this group being relatively stable in terms of symptoms, they still had moderate levels of disability, as indicated by the GAS score. Lower levels of functioning in the patient contributed to greater caregiver burden. This is in keeping with research findings that acting out behaviour or negative symptoms in the patient is linked to greater burden in caregivers (Gopinath & Chaturvedi, 1992; Salleh, 1994; Winefield & Harvey, 1993).

Caregivers who used denial as a coping strategy experienced greater burden. Several studies have reported that the use of avoidance and denial coping methods results in greater burden and distress. (Hinrichsen & Lieberman, 1999; Scazufca & Kuipers, 1999; Sekharan *et al.*, 2001). On the other hand, caregivers who use less of denial are higher on

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wellbeing (Rammohan, et al.,2002). The caregivers in the present study were using denial as a coping strategy, despite being in contact with mental health services. This finding suggests that psychological intervention with family caregivers must focus on helping them to accept the illness and take a more active role.

The study is limited by the small sample size and it's cross sectional design. The caregivers were screened for the presence of a psychiatric disorder using a clinical interview and a formal assessment was not carried out. The psychological distress experienced by caregivers may have influenced their ratings of burden.

In conclusion, providing care to a family member with a long standing mental illness such as schizophrenia causes significant disruption in several domains of family life. There are concerns specific to parents and spouses that need to be addressed. Family intervention programs for persons with schizophrenia, therefore, must be sensitive to the needs of individual patients as well as caregivers.

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