

Psychological well-being and burden in caregivers of patients with schizophrenia

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Received September 17, 2014. Accepted September 28, 2014

Abstract

Background: There is a definite paucity of Indian studies looking into the caregiver burden, psychological well-being, and the interface between them.

Objectives: This work aims to study the correlation between these variables.

Materials and Methods: The study sample included 100 patients with a diagnosis of schizophrenia and their caregivers, randomly selected from the patients admitted in the male and female wards of psychiatric center, Jodhpur, as per inclusion and exclusion criteria. Burden Assessment Schedule and Psychological General Well-Being Index were used for the study.

Results: Eighty percent of the caregivers experienced moderate levels of burden. The burden was higher among older ($r = 0.334$) caregivers and spouse ($p < 0.0001$). Psychological well-being was low in older caregivers ($r = -0.44$) and those with lower educational status, and higher in the siblings ($p = 0.002$). A strong negative correlation was found between burden and psychological well-being ($r = -0.81$).

Conclusion: Quality of care given to the individuals with schizophrenia depends on their primary caregiver. It thus becomes essential to plan interventions that would reduce their burden of care and thus improve their psychological well-being.

KEY WORDS: Caregivers, Burden, Psychological Well-being, Schizophrenia

Introduction

A severe and chronic mental illness like schizophrenia has a devastating impact on the patient as well as his or her family members. The capacity for social relationship is often diminished, and employment opportunities are reduced.^[1,2] Modern methods of treatment have helped a large number of patients to recover or to improve significantly, but many continue to show deficits in several areas of functioning.

Patient's relatives experience a range of emotions, from loss and grief to guilt and anger. Like the patient they also feel isolated and stigmatized.^[3,4] Caregivers are often bound by kinship obligations to adopt certain duties and responsibilities that are far in excess of those normally associated with a family role at a particular stage.^[5-7] If caregiving is prolonged

(and in many health conditions, it can last until one of the pair dies), problems can be exacerbated, things may not get better with time. A further difficulty is that caregivers find that they have no choice.^[8] All these aspects of caregiving make it burdensome, although, rarely it can be a source of joy and satisfaction. Caregiver burden has thus been defined as "the presence of problems, difficulties or adverse events which affect the life (lives) of the psychiatric patients' significant others (e.g. members of the household and/or the family)."^[9] There are many other similar definitions, but all share a common underlying frame of reference.

Historically and in contrast to their Western counterparts, Indian caregivers have never been systemically excluded from the treatment of people with mental illness. A large part of the mental health care had thus always taken place in the community with the family as the primary care provider. This is due to the social and cultural milieu as well as the inadequate existing mental health infrastructure.^[10] Families in India are involved in most aspects of care for persons with several mental illnesses. They are recognized as having a prominent role to play in decisions regarding engagement or disengagement from the treatment process, supervision of medication, providing day-to-day care and emotional support to the individual.^[11,12]

Access this article online

Website: <http://www.ijmsph.com>

DOI: 10.5455/ijmsph.2015.0817201416

Quick Response Code:



Burden has an objective and a subjective component.^[13,14] Subjective burden is comparatively less. Clinical factors appear to determine the extent of burden and demographic factors the pattern of burden.

A stress and coping framework is helpful for mental health professionals to understand the range of adaptational responses made by family members to the stress of caring for a mentally ill relative.^[15,16] This perspective views individuals as responding to situations that are perceived as taxing or as exceeding their ability to contend with them.^[17] Caring for a relative with schizophrenia is viewed as a chronic stressor. For family members, coping involves continual adjustments to the frequent crises and disruptions in family life.^[18] The presence of limited resources can further compound the problem, resulting in financial and other hardships.^[19] Caregivers experience considerable amount of distress as a result of the caregiving role, and are vulnerable to developing minor psychiatric disorders such as anxiety and depression.

Caregiver burden, psychological well-being, and the interface between them need to be assessed to develop strategies to aid in caregiving. Though Western studies have looked into the relationship between these variables, there is a definite paucity of Indian studies in this field. Moreover, barring a few studies, only few of them have looked into the correlation between these variables. This study aims to evaluate the psychological well-being and burden in caregivers of the patients with schizophrenia and the correlation between these variables.

Methodology

Population

The study was conducted in the psychiatry department of Dr. S.N. Medical College, Jodhpur. A total of 100 patients with a diagnosis of schizophrenia and their caregivers were randomly selected from the patients admitted in the male and female wards of the psychiatric center, Jodhpur, after obtaining an informed consent from them.

Sampling Design

Non-probability purposive sampling

Inclusion and Exclusion Criteria

First-degree relatives (parents, siblings, or offspring) and spouses of the index patients, diagnosed as a case of schizophrenia as per the *International Classification of Diseases*, 10th Revision (ICD-10) criteria, actively involved in the care of the patient and living with the patients for at least 6 months before the assessment were included in study. Patients with any other comorbid psychiatric or medical illness or a substance-induced disorder were excluded from the study.

Tools for Study

(A) *Patient's Sociodemographic Performa*. A sociodemographic performa was developed to record details, such as age, gender, education, marital status, and area of residence,

about the patient. Information regarding diagnosis and duration of illness was also recorded.

(B) *Caregiver Sociodemographic Performa*. This was used to record information about the caregiver, such as relationship with the index patient, age, gender, education, duration of marriage (for spouse caregivers), and duration of care.

(C) *Burden Assessment Schedule*. The Burden Assessment Schedule (BAS) was developed at the schizophrenia Research Foundation, Chennai, India, to assess caregiver burden. The scale was developed using the stepwise ethnographic exploration method, to develop items that are contextual and reflected opinions of the caregivers themselves rather than those of the researchers. There are 40 items that are rated on a three-point scale, marked 1–3. Some of the items are reverse-coded. The score ranges from 40 to 120, with higher scores indicating higher burden. The BAS had been validated against the family burden schedule of Pai and Kapur^[20] and the correlations ranged from 0.71 to 0.82 for most items. Inter-rater reliability for the scale was 0.80 (κ , $p < 0.01$).^[21] The test–retest reliability computed for 3 months was 0.91, and the value of α coefficient was 0.92.

The BAS was used in this study because it was developed in the Indian setting and thus helps to understand and interpret burden in the cultural context.

(A) *Psychological General Well-Being Index*. The Psychological General Well-Being Index (PGWBI) is a 22-item health-related quality of life (HRQoL) questionnaire that gives a self-perceived evaluation of psychological well-being expressed by a summary score. The original PGWBI consists of 22 self-administered items, rated on a six-point scale, that assess psychological and general well-being of respondents in six HRQoL domains: anxiety, depressed mood, positive well-being, self-control, general health, and vitality. Each domain is defined by a minimum of three or a maximum of five items. The scores for all domains can be summarized to provide a summary score, which reaches a maximum of 110 points, representing the best achievable “well-being.”

Statistical Methods

Descriptive statistical analysis was carried out in the present study. Results on continuous measurements are presented as mean \pm SD, and results on categorical measurements are presented in number (%). Significance is assessed at 5% level of significance. The statistical tests used to find the significance of study parameters include unpaired *t*-test and analysis of variance, whereas Pearson's correlation coefficient was computed to find correlations between different variables.

Results

Table 1 shows the sociodemographic characteristics of the total patient sample. Of patients, 46% were aged between 20 and 29 and 34% were between 30 and 39 years. The majority of patients were male (84%) with only 16% of the patients being female. The majority of the patients had low educational

Table 1: Sociodemographic data of total patient sample

Variables	No. of patients (n = 100)	Percentage
Age (years)		
20–29	46	46
30–39	34	34
40–49	10	10
50 and above	10	10
Gender		
Male	84	84
Female	16	16
Education		
Illiterate	24	24
Primary	34	34
Middle (up to 8th)	20	20
Sr. Secondary	8	8
Graduate and above	14	14
Residence		
Rural	74	74
Urban	26	26
Occupation		
Employed	30	30
Unemployed	70	70

level with 24% of them being illiterate; 74% patients were from rural background, 26% were from urban background; 70% of the patients were unemployed.

Table 2 shows the sociodemographic characteristics of the caregivers. More than one-third (36%) of the caregivers were aged 50 years or above whereas 22% were aged between 40

Table 2: Sociodemographic details of the caregivers

Variables	No. of caregivers (n = 100)	Percentage
Age (years)		
20–29	18	18
30–39	24	24
40–49	22	22
50 and above	36	36
Gender		
Male	78	78
Female	22	22
Education		
Illiterate	36	36
Primary	20	20
Middle (up to 8th)	20	20
Sr. Secondary	10	10
Graduate and above	14	14
Residence		
Rural	74	74
Urban	26	26
Occupation		
Employed	74	74
Unemployed	26	26

Table 3: Relationship of caregivers with the patient

Relationship	No. of caregivers (n = 100)	Percentage
Parents	42	42
Spouse	20	20
Sibling	34	34
Other (son/daughter)	4	4

and 49 years. The majority of caregivers were male (78%) with only 22% of the caregivers being female; 74% of the caregivers were employed.

Table 3 describes the distribution of caregivers on the basis of their relationship with patients. Majority of the caregivers include parents (42%) and siblings (34%), 20% were spouses of patients and only 4% were son or daughter.

Table 4 shows the duration of caregiving. About two-thirds of the entire population of patients had been provided care for less than 10 years with 58% of them having provided care for less than 5 years. The mean duration of care given was 6.62 ± 5.37 years.

The mean burden score in the caregivers was 71.28 ± 10.40 . Of the caregivers, 80% experienced moderate levels of burden and distress whereas 20% experienced severe burden and distress.

Table 5 shows the correlation between sociodemographic variables and level of burden in caregivers. A positive correlation was found between the age of caregivers and the level of burden ($r = 0.334$), which was statistically significant. No statistically significant difference was found in the level of burden between male and female caregivers. No statistically significant difference was found in the level of burden on the basis of educational status of the caregivers. No statistically significant difference was found in the level of burden between urban and rural caregivers.

Table 6 shows the distribution of burden on the basis of caregivers' relationship with the patient and mean duration of caregiving. The level of burden was highest among spouses followed by the parents of the patients whereas siblings reported a relatively lesser burden. A positive correlation was found between the duration of care and the level of burden ($r = 0.29$), which was statistically significant.

Table 7 shows the correlation between sociodemographic variables and their psychological well-being in caregivers. A negative correlation was found between the age of caregivers and psychological well-being ($r = -0.44$), which was statistically significant. No statistically significant differ-

Table 4: Duration of caregiving

Duration of caregiving (years)	No. of caregivers (n = 100)	Percentage
0–5	58	58
6–10	16	16
> 10	26	26

Table 5: Correlations between caregiver sociodemographic variables and burden

Variables	Mean BAS \pm SD	Statistical significance
Age (years)		
20–29	64.11 \pm 8.81	$r = 0.3341$
30–39	67.00 \pm 10.57	$p = 0.02(S)$
40–49	77.55 \pm 10.22	
50 and above	73.89 \pm 8.29	
Gender		
Male	70.10 \pm 10.63	$t = 1.706$ $p = 0.104 (NS)$
Female	75.45 \pm 8.75	
Education		
Illiterate	73.44 \pm 10.27	$p = 0.131 (NS)$
Primary	75.40 \pm 6.08	
Middle (up to 8th)	70.10 \pm 12.47	
Sr. Secondary	69.00 \pm 9.95	
Graduate and above	63.00 \pm 10.17	
Residence		
Rural	71.68 \pm 11.02	$t = 0.4501$ $p = 0.655 (NS)$
Urban	70.15 \pm 8.69	

BAS, the Burden Assessment Schedule; NS, not significant.

ence was found in the psychological well-being between male and female caregivers.

Caregivers with higher educational status experience better well-being with mean PGWB score for illiterate caregivers being 53.28 ± 13.72 whereas that for graduate and postgraduate caregivers was 76.43 ± 10.53 and the difference between the groups was statistically significant. No statistically significant difference was found in the psychological well-being between urban and rural caregivers. To the best of our knowledge, no other study has looked at the correlation between caregiver's residence and their psychological well-being.

Table 6: Correlation of burden on basis of caregiver's relationship with the patient and duration of care

Variables	Mean BAS \pm SD	Statistical significance
Relationship		
Parents	72.62 \pm 7.50	$p < 0.0001 (S)$
Spouse	82.20 \pm 8.48	
Sibling	63.47 \pm 8.78	
Other (son/daughter)	69.00 \pm 4.24	
Mean duration of caregiving		
6.62 \pm 5.37	71.28 \pm 10.40	$r = 0.29$ $p = 0.04 (S)$

BAS, the Burden Assessment Schedule; S, significant.

Table 7: Correlations between caregiver sociodemographic variables and psychological well-being

Variables	Mean PGWB \pm SD	Statistical significance
Age (years)		
20–29	69.00 \pm 15.17	$r = -0.44$
30–39	66.67 \pm 13.02	$p = 0.001 (S)$
40–49	54.18 \pm 13.52	
50 and above	53.33 \pm 12.86	
Gender		
Male	60.08 \pm 15.28	$t = 0.463$ $p = 0.65 (NS)$
Female	57.64 \pm 16.11	
Education		
Illiterate	53.28 \pm 13.72	$p = 0.002 (S)$
Primary	52.80 \pm 11.87	
Middle (up to 8th)	61.40 \pm 14.86	
Sr. Secondary	67.40 \pm 10.57	
Graduate and above	76.43 \pm 10.53	
Residence		
Rural	58.62 \pm 14.82	$t = 1.134$ $p = 0.26 (NS)$
Urban	64.23 \pm 16.83	

PGWB, the Psychological General Well-Being Index; NS, not significant; S, significant.

Table 8 shows the distribution of psychological well-being on the basis of caregivers' relationship with the patient and mean duration of caregiving. Highest well-being was found in the siblings whereas spouses reported least well-being scores. A negative correlation was found between the duration of care and the psychological well-being ($r = -0.17$) though it was statistically insignificant ($p = 0.24$).

A strong negative correlation was found between burden and psychological well-being ($r = -0.81$), which was statistically significant.

Table 8: Correlation of psychological well-being on basis of caregiver's relationship with the patient and duration of care

Variables	Mean PGWB \pm SD	Statistical significance
Relationship		
Parents	55.09 \pm 12.93	$p = 0.002 (S)$
Spouse	50.10 \pm 12.74	
Sibling	69.82 \pm 14.32	
Other (son/daughter)	66.00 \pm 15.56	
Mean duration of caregiving		
6.62 \pm 5.37	59.54 \pm 15.33	$r = -0.17$ $p = 0.24 (NS)$

PGWB, the Psychological General Well-Being Index; NS, not significant; S, significant.

Discussion

The majority of patients were male with low educational status. About three-fourths of them were from rural background and majority of them were unemployed, which indicates the occupational and functional impairment caused by a chronic illness like schizophrenia. Majority of caregivers were male and employed. The average duration of care coincided with the duration of illness in the patient, indicating that these caregivers have been the stable and long-term providers of care.

Providing care for the index patient has had a detrimental impact on the caregiver's own health, and caregivers reported that they spent less time on taking care of their own health due to increased involvement in caring for the index patient. Adverse effects of care-giving for the patient on the caregiver's own health, both physical and mental, have been reported in research literature on caregivers in both Indian context^[22–24] and Western settings.^[25–28]

A statistically significant positive correlation between the age of caregivers and the level of burden implies that the level of burden increases with the age of caregivers. This is in accordance with that reported in a Chinese study by Juvang *et al.*^[29] and an Indian study by Rammohan *et al.*^[30] When caregiver becomes older, they are worried about who will take care of their ill family member in the future. Older caregiver also cannot provide good care to the ill member. Though it is in contrast to the finding of Martyn-Yellowe^[31] and Roychaudhuri^[23] where burden was experienced more in the younger age group.

In contrast to the present study, studies by Nehra *et al.*^[32] and Kumar *et al.*^[33] showed burden to be higher in female caregivers. Unlike our study, a Chinese study by Juvang *et al.*^[29] and an Indian study by Rammohan *et al.*^[30] showed a negative correlation between the caregivers' education level and the level of burden. It was found that families experienced equal burden irrespective of the residential settings, which is in accordance to that reported in a study by Ali and Bhatti.^[34] However, somewhat different results were found in other studies such as the study by Ranga Rao^[35], which showed burden to be higher in urban caregivers.

Spouses were reported to have higher burden than parents of the patients, a finding similar to that reported in the studies by Rammohan *et al.*^[30] and Jayakumar *et al.*^[36] Similar to a Chinese study by Juvang *et al.*^[29] and an Indian study by Vohra *et al.*^[37], a positive correlation was found between the amount of time that caregivers spent with their family member and objective burden faced by them.

The older caregivers have a poorer psychological well-being. They also feel more burdened. This is in contrast to the studies by Magaña *et al.*^[38] and Gopinath and Chaturvedi^[39], which reported higher distress among younger caregivers. In contrast to our study, Marimuthu *et al.*^[24] reported that 53% of the caregivers with psychiatric morbidity were females, and a study by Shankar *et al.*^[40] also reported global disability to be higher among females. Low educational level of the caregiver

was reported as a correlate of psychiatric morbidity, similar to a study by Marimuthu *et al.*^[24] However, somewhat different results were found in another study by Gopinath and Chaturvedi^[39], which showed distress to be higher in caregivers with higher education.

Parents as a caregiver reported higher well-being compared to spouses but lesser than siblings, whereas some studies reported psychological well-being to be significantly more in spouses when compared to parents.^[30] In a study conducted by McCleery *et al.*^[41], it was reported that the duration of illness does not control the caregivers' well-being. However, some studies differ: a study by Martens and Addington^[42] reported that poor psychological well-being was associated with short duration of illness.

Caregivers who were higher on burden reported lower level of well-being.^[43,44] This is in accordance with a study by McCleery *et al.*^[41] showing psychological well-being to be inversely proportionate to the caregiver burden. Madianos and Economou *et al.*^[45] also reported that psychological well-being was impaired in those who had high level of burden and negative family atmosphere.

Conclusion

This study showed that 80% of the caregivers have experienced moderate levels of burden. Older caregivers experienced higher burden whereas gender and educational status exerted no significant effect on burden. The burden was significantly higher among spouses followed by parents, and the level of burden was positively correlated to the duration of care.

It was also found that psychological well-being was low in older caregivers and those with lower educational level. Highest well-being was found in the siblings whereas spouses reported least well-being scores.

A strong negative correlation was found between burden and psychological well-being, thus showing that a higher level of burden in caregivers resulted in poor psychological well-being.

One limitation of the present study is that it was carried out in a tertiary-care hospital in an urban setting and hence the results cannot be generalized to the population at large. The size of the sample was small and a multi-centered study with a larger sample size is required.

The findings of this study show that the quality of care given to the individuals with schizophrenia depends on their primary caregiver. Thus, it becomes essential to plan interventions that would reduce their burden of care and improve the psychological well-being.

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How to cite this article: Gupta A, Solanki RK, Koolwal GD, Gehlot S. Psychological well-being and burden in caregivers of patients with schizophrenia. *Int J Med Sci Public Health* 2015;4:70-76

Source of Support: Nil, **Conflict of Interest:** None declared.