Original Article

Caregiving burden and social support among caregivers of schizophrenic patients

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ABSTRACT

Background: Schizophrenia is a dark shadow in an individual’s life. The number of people with schizophrenia in the world, particularly in developing countries, is increasing. The patients with schizophrenia are frequently hospitalized and usually need long term care and treatment in order to reduce negative impacts. Families in India are involved in most aspects of care for persons with several mental illnesses. Families not only provide practical help and personal care but also provide emotional support to their relatives. Material and Methods: Quantitative research approach and correlational research design was used. The sample of 100 caregivers of schizophrenia was taken with purposive sampling technique. The structured self-report tools including a rating scale to assess caregiving burden & a rating scale to assess social support were administered to the caregivers of schizophrenic patients to collect the data. Results: It was found that the caregiving burden and social support are negatively correlated (r = -0.45) and majority of caregivers (50%) of schizophrenic patients suffer from severe and moderate level of caregiving burden. However, most of the caregivers (62%) of schizophrenic patients have low acuity of social support where as no one has been found with high acuity of social support. The level of burden experienced was significantly associated with duration of illness and gender.

Key words: caregiving burden, social support, caregiving burden

Introduction

“They say when you talk to God it’s prayer, but when God talks to you, it’s schizophrenia”
Fox Mulder

For long popularly mental illness was regarded as resulting from sin or curse and the social stigma was associated with it, did not permit family members to actively seek appropriate psychiatric treatment. Today a gradual reversal of this trend is beginning to appear. However due to the nature of mental illness caring for a family member with mental illness can cause immense burden on other family members.¹

A severe mental illness like schizophrenia has a devastating impact on the patient as well as his/her family members. Thus is due to chronic nature of the illness and the long term treatment it often involves. Patient extensive problems related to both positive symptoms such as aggressive behaviour, delusions, hallucinations and negative symptoms such as poor motivation and inadequate self care. In addition, the disease may relapse during treatment and recovery. Therefore, patients with schizophrenia are frequently hospitalized and usually need long term care and treatment in order to reduce negative impacts.²

Schizophrenia is found in all societies and geographical areas and is a major cause of death of patients. About 15 % of new admissions in mental hospitals are schizophrenic patients. It has been estimated that patients diagnosed as having schizophrenia occupy 50% of all mental hospital beds. About 3-4 per 1000 in every community suffer from schizophrenia.² About 1% of the general
population stands the risk of developing this disease in their life time. India rank at the upper stages as per the prevalence rate of schizophrenia is concerned. Amongst the epidemiological studies in India, SOFFUC (study of functional psychosis in urban community) in Madras is the most confounding one. It was a multistage census survey. The prevalence rate of schizophrenia was estimated at 2.62/1000.³

Burden of family caregivers leads to negative consequences not only for themselves but also for patients, other family members, and health care system. For caregivers, burden negatively affects caregiver’s physical, emotional, and economic status. Furthermore, their negative quality of life have impacted on poor caring, mistreatment or behaving violently to the patients which can cause patients relapse. Therefore, this review paper will include theoretical foundation of burden, in particular when caring for persons with schizophrenia, and its related factors.⁴

Social support is the perception and actuality that one is cared for, has assistance available from other people, and that one is part of a supportive social network. These supportive resources can be emotional (e.g., nurturance), tangible (e.g., financial assistance), informational (e.g., advice), or companionship (e.g., sense of belonging). Social support can be measured as the perception that one has assistance available, the actual received assistance, or the degree to which a person is integrated in a social network.⁵

In comparison to families of patients with other chronic diseases, families of patients with schizophrenia report higher subjective and objective burden in conjunction with lower support from the social network and professionals. Both subjective and objective aspects of individual quality of life and perceived family burden are substantially affected by access to evidence-based treatments, quality of available social supports, financial circumstances and close relationships.⁶

**Aim of the study**

The aim of the study is to find out the correlation between caregiving burden and social support among caregivers of schizophrenic patients.

**Assumption**

There is increase in caregiving burden with decrease in social support or increase in caregiving burden leads to decreased social support.

**Methodology**

*Research design:* A non-experimental i.e. correlational research design was used.

*Research setting:* New Saini Psychiatric Hospital, Hoshiarpur, Punjab.

*Sample & sampling technique:* Sample for the study consisted of 100 caregivers and selection was on the basis of purposive sampling technique.

**Inclusion criteria**

- Caregivers who are in age range of 20-60 Years.
- Caregivers who are closely related and directly involved in care of schizophrenic patients.

**Exclusion criteria**

- Caregivers who are not willing to participate.
- Caregivers of schizophrenic patients with co-morbid conditions.

**Brief description of tool**

- Socio-demographic profile and clinical data
- Structured rating scales to assess Caregiving burden and social support among caregivers of schizophrenic patients.

*Section 1: Socio Demographic Profile and clinical data:* It comprised of items for obtaining personal information of the caregivers of schizophrenic patients i.e. age, gender, education, occupation, marital status, family income (in rupees/month), duration of illness (in years), relationship to care recipient.

*Section 2:* It was consisted of structured self-report rating scales to assess caregiving burden and social support among caregivers of schizophrenic patients. It consists of 2 parts:

**Part 1: Rating Scale to assess Caregiving Burden among Caregivers of Schizophrenic Patients:** The tool was constructed after reviewing standardized tools such as burden assessment schedule (WHO), caregiver burden inventory (Novak and Guest), caregiver burden assessment and caregiver burden scale. It was a structured 5 point self report rating scale including 34 items with
dimensions as caregiving responsibilities/time dependency burden (1-4 items), physical health burden (5-10 items), social relationship burden (11-16 items), emotional burden (17-30 items) and financial burden (31-34 items).

**Part 2: Rating Scale to assess Social Support among Caregivers of Schizophrenic Patients**

The tool was constructed after thorough review of standardized tools such as social support questionnaire (PGI) and multidimensional scale of perceived social assessment. It consisted of structured 5 point self report rating scale to assess social support among caregivers of schizophrenic patients including 20 items composed of dimensions related to emotional support (1-13 items), tangible support (14-17 items) and appraisal social support (18-20 items).

**Reliability of tool**

Reliability of structured self report tools were computed by test-retest method. The reliability of rating scale to assess caregiving burden was 0.98 and reliability of rating scale to assess social support was 0.96. Thus the tools were reliable.

**Results**

**Table 1: Percentage Distribution, Mean score, Mean score percentage and Rank order of caregiving burden among caregivers of schizophrenic patients**

<table>
<thead>
<tr>
<th>Levels of Caregiving Burden</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>No burden (0-34)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Mild level of burden (35-68)</td>
<td>01</td>
<td>01</td>
</tr>
<tr>
<td>Moderate level of burden (69-102)</td>
<td>50</td>
<td>50</td>
</tr>
<tr>
<td>Severe level of burden (103-136)</td>
<td>49</td>
<td>49</td>
</tr>
</tbody>
</table>

Table 1 shows the Percentage Distribution, Mean score, Mean score percentage and Rank order of caregiving burden among caregivers of schizophrenic patients. It was concluded that majority of caregivers of schizophrenic patients suffer from severe (50%) and moderate (49%) level of caregiving burden. Besides, no one is out of burden due to caregiving. It was also found that caregivers of schizophrenic patients have high caregiving burden with very least difference in areas of physical health burden and time dependency burden with mean score percentage 82.29 and 80.31.

**Table 2: Percentage Distribution, Mean score, Mean score percentage & Rank order of social support among caregivers of schizophrenic patients**

<table>
<thead>
<tr>
<th>Acuity of Social Support</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>No acuity (0-20)</td>
<td>23</td>
<td>23</td>
</tr>
<tr>
<td>Low acuity (21-40)</td>
<td>62</td>
<td>62</td>
</tr>
<tr>
<td>Moderate acuity (41-60)</td>
<td>15</td>
<td>15</td>
</tr>
<tr>
<td>High acuity (61-80)</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Maximum score = 80
Minimum score = 0

It can be concluded that most (52%) of the caregivers of schizophrenic patients have low acuity of social support where as no one has been found with high acuity of social support. It was also inferred that caregivers of schizophrenic patients has little high emotional social support (mean score percentage 46.35) as compared to appraisal support and the least acuity was with tangible social support (mean score percentage 07.81).

This indicated that caregiving burden and social support were moderately negatively correlated (r =...
Table 4. Social Support Score

<table>
<thead>
<tr>
<th>Dimensions of Social Support</th>
<th>MaximumScore</th>
<th>MeanScore</th>
<th>MeanScore %</th>
<th>Rank order</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional Social Support</td>
<td>52</td>
<td>24.10</td>
<td>46.35</td>
<td>1</td>
</tr>
<tr>
<td>Tangible Social Support</td>
<td>16</td>
<td>1.25</td>
<td>07.81</td>
<td>3</td>
</tr>
<tr>
<td>Appraisal Social Support</td>
<td>12</td>
<td>3.21</td>
<td>26.75</td>
<td>2</td>
</tr>
</tbody>
</table>

Maximum score = 136
Minimum score = 0

Table 5: Correlation between caregiving burden and social support among caregivers of schizophrenic patients

<table>
<thead>
<tr>
<th>Variables</th>
<th>Mean Score</th>
<th>Mean Score %</th>
<th>r</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiving Burden Social Support</td>
<td>100.14</td>
<td>73.63</td>
<td>-0.45</td>
</tr>
<tr>
<td>Social Support</td>
<td>28.56</td>
<td>35.7</td>
<td></td>
</tr>
</tbody>
</table>

Maximum score for caregiving burden = 136
Maximum score for social support = 80

According to Marital status, in the present study it was found that marital status has no statistical significant impact on caregiving burden (p=0.1978). In the similar context Srivastava and Kar et al revealed that marital status had no impact. Similarly, occupation has no statistical significant impact on caregiving burden (p=0.8057). Similarly Yusuf et al stated that there is no statistical significant impact of employment on caregiving burden.

According to Duration of illness (in years), in the present study it was found that it has statistical significant impact on caregiving burden (p=0.0149). In the same manner Kar et al also reported that duration of illness has statistical significant impact on caregiving burden. On the other hand, some studies found that patient’s ‘duration of illness was not statistically significantly correlated with caregiver’s GHQ-12 and IEQ subscale scores.

The present study revealed that most of the caregivers of schizophrenic patients had low acuity of social support. Similar findings were given by Magliano et al and Snow-Spracklin. According to age, in the present study it was concluded that age, gender has no statistical significant impact on social support (p=0.139). Similar findings are given by Okamoto and Tanaka that age and gender has no significant impact on social support. In the present study it was concluded that family income and education has no statistical significant impact on social support (p=0.199), (p=0.194). In the same context Lueboonthavatchai and Lueboonthavatchai stated that family income and education had no statistical significant impact on social support.

Duration of illness (in years), in the present study it was found that it has significant impact on social support (p=0.0006). In the same manner, studies by Lueboonthavatchai and Lueboonthavatchai and Snow-Spracklin, the duration of illness has significant impact on social support. According to Relationship to care recipient, in the present study it was found that it has no statistical significant impact on social support (p=0.9154). Similar findings were
given by Okamoto and Tanaka\textsuperscript{13} that the relationship to care recipient has no impact on social support.

It was concluded that there is moderate negative correlation between caregiving burden and social support ($r = -0.46$). Similar findings were given by Bhatia and Jena\textsuperscript{14} that satisfaction with support network was inversely related to objective and subjective measures of burden. Similarly, Caregiver physical and emotional dimension of burden depicted significant, negative correlations with total network support ($r = -0.26$).

**Conclusion**

The data suggests that caregiving burden has negative correlation with social support which means that caregivers who have high level of caregiving burden have low acuity of social support. It was found that majority of caregivers of schizophrenic patients have moderate and severe levels of caregiving burden. Besides, no one is out of burden due to caregiving. Although caregivers of schizophrenic patients have high caregiving burden with very least difference in areas of physical health burden and time dependency burden. The least level of burden as compared to other areas is found in financial area. However, most of the caregivers of schizophrenic patients have low acuity of social support where as no one has been found with high acuity of social support.

**Limitations**

1. The study was restricted to caregivers of schizophrenic patients in New Saini Psychiatric Hospital, Hoshiarpur.
2. Size of sample was 100; therefore it was difficult to make broad generalizations.

**References**

Caregiver of Psychiatric In-Patients. Dept of Psychiatry. Mental Health Institute SCB Medical College Hospital: Cuttack, 2007.


