Burden of schizophrenia on caregivers in Nepal

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ABSTRACT

Schizophrenia is one of the severest form of psychiatric disorder. The disorder affects not only the patient but the family also. This study is performed to assess the burden faced by care givers of schizophrenic patients. Family burden interview schedule was used in this study. There were forty patients in study, twenty six male and fourteen female. Forty caregivers were interviewed for assessment of burden, among whom thirty were female and ten male. And to compare burden forty care givers of bipolar patients were taken. Female parents were the most usual care givers, with average age of 58.3 years and most of them were housewives. The most burden were in the area of finance and family dynamics and overall burden was moderate.

Keywords: schizophrenia, family, care givers, burden.

INTRODUCTION

Schizophrenia is a chronic psychosis in which the patient losses contact with reality. It is a devastating illness, often resulting in a loss of social functioning in affected individuals. The family remains the major source of care for the mentally ill. The sufferer’s family has a profound effect on their illness. People engaged for caring those with schizophrenia include parents, spouse, siblings and offspring. Having a schizophrenic in a family also affects the roles and interactions within the family. Family with schizophrenic patient faces lots of burden which includes care burden, fear and embarrassment about illness signs and symptoms, uncertainty about course of the disease, lack of social support, and stigma. Burden refers to the negative impact of the individual’s mental illness on the entire family.¹² The burden could be in the form of loss of income, employment; expenses, reduced productivity, days out of role, emotional strain, and disturbed social relations. There is also the constant fear that recurrence of illness may cause sudden and unexpected disruption of the lives of family members. They face challenge in context of economic as well as quality of life. The care givers have to take care of their every activities right from their symptoms to their daily activities. Careers have to dedicate most of their time to the patient because of whom they tend to neglect themselves and make their own life chaos. A reduction of burden on families improves the chances of schizophrenics being accepted in the family.³ And improving the way families cope with the burden of looking after the schizophrenic at home has a beneficial effect on the course of schizophrenia.⁴ There is no such study of family burden in schizophrenia has been reported in Nepal. The main aim of conducting this study is to know the burden of schizophrenic patients’ families in Nepalese society.

MATERIALS AND METHODS

This study was a unmatched case control study and conducted between 1st June 2012 to 30th Nov 2012 at Manouthan Sewa Kendra, a transit home located in Bhaktapur district. The transit home was established in 2008 A.D. and caters to patients from same district and adjoining districts. The centre has 25 bed capacity and runs various programs like inpatient treatment, outpatient treatment, social skill training, vocational training, awareness programs, home visit program, counseling etc. The patients and nearest care giver who spent maximum time with patient were taken from home visit program. Those patients whose duration of disorder is more than two years and the care givers who volunteered to take part in study were included. Absence of disabling physical illness and other psychiatric disorders were also required for the study population. Demographic details of the patients and care giver and disease characteristics were recorded into a socio-demographic proforma by the psychologist during home visit. To assess the burden Pai and Kapur’s Family Burden Interview schedule was utilized.⁵ It is a semi structured interview schedule which consists of twenty four items grouped under six categories: 1 financial burden, 2 disruption of routine family activities, 3 disruption of family leisure, 4 disruption of family interaction, 5 effect on physical health of others and 6 effect on mental health of others. Each item is rated on three point scale, where 0 is no burden and 2 is severe burden. To compare the burden forty care giver of bipolar disorders patient were taken and their socio demographic details were recorded and family burden interview schedule administered.
RESULTS

The total number of patient in study period was forty. The socio demographic details of patients were shown in Table-1. There were 26 males and 14 females. Mean age of male schizophrenic patient was 34.2 years and females 33.6 years. 20 male patients has duration of illness 0-5 years, 6 has illness of 5-10 years duration.12 female patients has history of illness of 0-5 years duration, 2 had duration of 5-10 years of illness.23 male patients were unmarried, 2 married and 1 divorced. 12 female patients were unmarried, 1 married, 1 divorce. Similarly most of the patients were illiterate or with primary level of education. Only one patient has college level of education.

Table-2 shows the characteristics of care givers and control group. Females illiterates comprise the most of care givers with mean age of 58.3 years. Most of the care givers have occupation under the heading others which includes unemployed and house wives.

Table-3 illustrates the relation to patient and parents outnumber other care takers in both group. Areas of burden and score were shown in Table-4. The care givers of schizophrenia were of opinion of increase burden with aspect to financial burden, disruption of family activities, family leisure and family interaction. The least burdensome were in effect on physical health and mental health of others in both groups. It gives clear picture that there is an evidence on financial burden and other family related issues among the family members of schizophrenic individuals.

Table-5 shows the overall burden, 25 care takers in schizophrenic patients says moderate burden, 13 reports of no burden and 2 severe burden. In control group no burden was reported by 36 care takers, 2 severe burden and 2 moderate burden. The moderate burden seems to higher in care givers of schizophrenic patients with p value <0.05.

Table-4: family burden

<table>
<thead>
<tr>
<th>Areas of burden</th>
<th>Schizophrenia (n=40)</th>
<th>control (n=40)</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>range</td>
<td>mean</td>
<td>SD</td>
</tr>
<tr>
<td>Financial burden</td>
<td>2-8</td>
<td>4.90</td>
<td>2.30</td>
</tr>
<tr>
<td>Disruption of routine family activities</td>
<td>0-10</td>
<td>4.75</td>
<td>2.60</td>
</tr>
<tr>
<td>Disruption of family leisure</td>
<td>0-7</td>
<td>3.25</td>
<td>2.10</td>
</tr>
<tr>
<td>Disruption of family interaction</td>
<td>0-6</td>
<td>3.52</td>
<td>1.6</td>
</tr>
<tr>
<td>Effect on physical health</td>
<td>0-3</td>
<td>0.68</td>
<td>0.08</td>
</tr>
<tr>
<td>Effect on mental health of others</td>
<td>0-2</td>
<td>0.92</td>
<td>0.07</td>
</tr>
</tbody>
</table>
DISCUSSION
This study is done to examine burden faced by schizophrenic patient’s family while taking care of them in our socio cultural context. Most of the research in this area has been done on the developed nation. This kind of study on the burden of career of schizophrenia is to our knowledge is first of its kind in our country.

Burden of care is more defined by its impact and consequences on caregivers. The early conceptualization of burden of care is divided into two distinct components, objective and subjective. Objective burden of care means effects on finance, health, routine and leisure of the family where as subjective burden means psychological and emotional impact of mental illness on family members. In addition burden of care involves subtle but distressing notions such as shame, embarrassment, feelings of guilt, and self blame.

In a family where there is a schizophrenic, patient is the central focus but we tend to neglect difficulty that the family is going through. The evidence available suggest that family burden in schizophrenia is well documented but poorly provided for. However family needs, although extensive, do not have overwhelmed service. It is clear that families feel an appreciable burden and find it difficult to cope with schizophrenia. They often lack knowledge about the nature of the patient’s illness and receive little help from professionals for the management of the patients’ behavior. Coping with the patients’ problems frequently results in adverse effects on physical and psychological health of the family members, so relatives should be provided with more information regarding illness and be given more support to alleviate the distress they feel. Within the family, it is often the women, in the role of wife or mother who is affected and has to bear significant part of family burden. Such impact becomes even more obvious in developing country like Nepal, where women are already disadvantaged. Many studies has shown that schizophrenic care givers experience burden.  

In our study most reported burden were in financial, disruption in family environment, which is similar to study done in Turkey and India. The characteristic of our society is traditional people are closely dependent to each other and female do take responsibility of all domestic issues. The nature of illness is chronic and patient has to take treatment for indefinite period of time, this will put family in financial burden. Having a mentally ill person in family put them in awkward position in society and neighborhood. The unpredictable behavior of patient is always on guard by family members. The Malaysian study found severe burden faced by primary care takers in following domain expenses of patient’s illness, patient using up another person’s holiday and leisure time, ill effect on general family atmosphere and patient’s behavior disrupting activities. A Nigerian study found greatest burden was on family routine and family interaction. Other study using involvement evaluation questionnaire the greatest care giver burden resulted from worries about patient, and least from supervisory obligations. Studies have shown current symptomatology showed the strongest relationship with caregiving and caregiver’s distress. Also predictors of burden on caregivers have been found to be associated with socio demographic and personality variables such as attributions, coping strategies or expressed emotions.

The overall burden as reported by caregiver was moderate in comparison to control group where most of the care givers says no burden. One of the possible reason for this could be that characteristic of illness and study population was taken from home visit program and were not actively psychotic. The chronic course of illness with severe loss of insight increases the extent of burden. And greater degree of burden compared to schizophrenia with an episodic course.

The conclusion of this study is that care givers of schizophrenic patient has moderate overall burden and burden in financial aspect and family dynamics. However our study does not tried to correlate the symptomatology and burden. The finding of this study could used to develop a comprehensive plan to manage such cases in future.

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