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Burden of Caregivers among the Mentally and Physically Ill Women

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ABSTRACT

Family caregivers play a major role in providing care giving assistance to ill persons and their families. Families are an integral part of the care system for persons with a chronic mental illness. Mental health professionals need to be aware of and address the stress borne by the family in caring for patients with mental illness as they treat the patient. The aim of the study was to assess the burden of caregivers among mentally and physically ill women. This is a cross sectional study. The sample size consisted of 65 caregivers of women with mentally ill and 50 caregivers of women with physically ill attending the both OPD (Psychiatric and Gynae & obstetric OPD) of Sir Sunder Lal hospital. Caregiver burden of women with mental illness was more than of physical illness. There was significant difference found in both groups of caregivers. Keeping in view of the findings of study, the following recommendation were made. There is a need for teaching skills in the form of problem solving and communication is also needed to promote the coping abilities.

Introduction

Families are an integral part of the care system for persons with a chronic mental illness (Shankar & Menon, 1993). Women take on a large part of care giving responsibilities (Jenkins & Schumacher, 1999), and caregivers who are younger and more educated experience greater burden (Gopinath & Chaturvedi, 1992). The burden upon caregivers for a mentally ill patient living at home was first acknowledged by Grad and Sainbury in the early 1960s (Krupnik, 2005). Family burden has been extensively explored for illnesses like Schizophrenia, Dementia and Cancer by researchers. The cost families incur in terms of economic hardships, social isolation and psychological strain are referred to as family burden. Review of literature available suggest that family burden in mental and neurological diseases have some common characteristics such as the fact that several cognitive and behavioural symptoms may occur both in brain disorders and schizophrenia and these have been found to be strong predictors of anxiety and depression in patient's relatives because of the inability of the relatives' difficulty in understanding the meaning of some psychiatric and neurological symptoms.

A caregiver has been defined as a family member who has been living with the patient, and has been closely involved in his/her activities of daily living, health care, and social interaction for more than a year (Department of Health and Human Services, 2005).

Burden may be defined as the presence of problems, difficulties or adverse effects which affect the lives of psychiatric patients' caregivers (Thara, 1998).

Caregiver is an individual who has the responsibility of meeting the physical and psychological needs of the dependent patient. Psychiatric patients need assistance or supervision in their daily activities and this often places a major burden on their caregivers, thereby placing the caregiver at a great risk of mental and physical health problems. The term "caregiver burden" is used to describe the physical, emotional and financial toll of providing care.

According to Lefley (1996) burden of family caregivers of mental illnesses is an endless burden to care givers. He identified three types of burden faced by the family caregivers such as: (I) Objective burden (II) Subjective burden (III) Burden of management of problems of client with mental illness. This study examines the differences in the experience of burden between caregivers of women having mentally and physically ill. The aim is to compare the burden on caregivers of mental illness and compare the same with women having physical illness requiring long term management. Gynaecological problem is the most common and a global problem affecting all ages and social classes. It imposes enormous physical, psychological, social, and economic burdens on individuals, families, and countries especially because of misunderstanding, fear, and stigma of mental illness. Caregivers also face multiple psychosocial and economic problems. Chronic mental disorder associated with health, social and financial burden for a long duration, affecting not only for patients but also for families, other caregivers, and the wider society. Caring for a family member who is having mental illness is an enduring stressor and causes considerable amount of burden.

The most common mental health consequences identified are depression, anxiety and burnout which occur when a caregiver slips beyond exhaustion or depression. Studies conducted showed that caregivers reported burden in different areas including effects on family functioning, social isolation, financial problems, and health. Most of the notable community-based studies proved that 18–47% of caregivers land in depression (Muscroft and Bowl, 2000).

Analysis of burden and coping of family provide for a real world clinical decision, application of research finding, and generation of nursing strategies, all geared to promote holistic caring. The ultimate goal of nursing care is to maintain and enhance client and family quality of life irrespective of nature of illness.

Method

The present study was conducted in the OPD of Psychiatry and Gynaecology departments of Sir Sunder Lal, Hospital,

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BHU, Varanasi. The cross sectional descriptive study comprised of all the care givers of both mentally and physical illness. The sample size consisted of 65 caregivers of mentally illness women and 50 caregivers with physical illness attending the both OPD of Sir Sunder Lal hospital. 65 caregivers of patients diagnosed, as mental illness according to ICD 10 criteria were selected from department of Psychiatry, Sir Sunder Lal Hospital, Banaras Hindu University and 50 caregivers of patients diagnosed as gynaecological problem" were selected from department of Gynae, Sir Sunder Lal Hospital, Banaras Hindu University. Only family caregivers (spouse, parent, child, or siblings of the patient), who are above 18 years and living with the patient for one year were included in the study. Duration of illness in both the groups was more than 6 months. Caregivers having chronic physical illness, past/current psychiatric illness, taking care of more than one chronically ill person in the family and unwilling to participate in the study were excluded from the study. Caregivers of patients having co-morbidity were also excluded from the study.

Demographic data Performa was constructed to collect the data. Burden assessment tool (Thara, 1998) is a standardized 40 item scale, which measures different areas of burden like financial burden of caregivers, occupation, patient behaviour, social relations, caregiver's health, family relations and emotional burden. Each item is rated on a three point scale (not at all, to some extent and very much). The scores range from 40 to 120, with higher scores indicating greater burden. All the tools were translated to Hindi and tried out on a similar population before use. Ethical clearance was obtained from competent authority. A pilot study was done on 10 subjects to ascertain the feasibility of actual study. Descriptive statistics (Mean, Standard deviation) and inferential statistics (Unpaired t test, Chi square) were used for the analysis.

Results

Data was collected from 115 samples (Group-1 caregivers of mentally ill women, N=65 and Group-2 care givers of physically ill women, N=50). Distribution of subjects was according to socio-demographic variables using frequency percentage and intensity of perceived burden in mean percentage score in both the groups. All caregivers were married and belonged to Hindu religion. Majority (17 out of 65) of the caregivers of patients having schizophrenia were taking care of patients for 0-2 years and majority (12 out of 50) of caregivers of patients having Menorrhagia were taking care of patients for 8 months.

The most common diagnostic categories in psychotic illness was schizophrenia (26.2%); These were followed by major depressive disorder with psychotic features (10.8%); Bipolar I disorder, most recent episode manic (7.7%); Bipolar I disorder, single mania episode (6%) and Brief psychotic disorder (6.6%). Non-psychotic illness was Generalized anxiety disorder 15.4%, Major depressive disorder without psychotic features (13.8%), Conversion disorder (9.2%), Obsessive compulsive disorder (6%) and Dissociative disorder (3.1%) (Table 1).

The most common diagnostic categories in physical illness was Menorrhagia (24.0%); These were followed by fibroid uterus (22.0%); vaginitis (16.0%); Dysfunctional Uterine bleeding and Dysmenorrhoea (10%) and ovarian cysts, ectopic pregnancy, pelvic inflammatory disease (4%), vaginal cysts, cervicitis, infertility (1%). (Table 2).

The mean scores of 'Burden of primary care givers' on the BASS are depicted in Table 3. The mean score of total burden for women with Mental illness was 70.27±15.68 (35-95) and for women with physical illness was 56.56±6.7 (47-70). The mean scores (Physical and mental health, external support, care giver routine, support of patient, taking responsibility, other relations patient behaviour, caregiver strategy and Total) of BASS of mental illness were significantly higher than corresponding scores of physical illness (Tables 3).

The mean age of onset and duration of illness of women with mental illness and physical illness are given in Table 4. The mean age of onset of mental illness was 27.03±7.15 years (6-39), and of physical illness was 28.72±6.72 years (20-40). The mean duration of mental illness was 42.66±42.69 (0-216) months, and physical illness of 5.78±7.51 (0-36) months. There was no significant difference between women with mental illness and physical illness with respect to age of onset of disease (Table 4). The mean duration of illness of mental illness was significantly greater than that of physical illness (Table 4).

Discussion

This study has tried to assess the burden of caregivers of mentally and physically ill women. In the present study burden assessment score of mental illness were significantly higher than corresponding scores of physical illness. The results of the current study show that the caregivers of patients having women with mental illness and physical illness experience significant amount of burden just like most of the studies reported in literature (Thomas, 1999). Seventy percent of the caregivers experienced moderate degree of burden, and 30% a severe degree of burden according to the burden assessment schedule (Manish, 2012). Majority of studies on burden of caregivers of patients having schizophrenia conducted so far report significant burden of caregivers with over 90% of families, experiencing moderate to severe burden (Provencher, 1996). Studies of caregivers of chronic patients have found levels of burden to be associated with greater severity of illness symptoms and longer duration of illness (Kugoh, 1991). In the current study, the mean duration of mental illness is more compare to physical illness. This difference is significant and it can be attributed to the time of onset of disease, which is early for mental illness and late for physical illness comparatively. The longer duration of mental illness might have contributed to the increased burden of the caregivers. Moreover, mental illness is a disease which is still having significant stigma attached to it. It may be possible that the extent of burden experienced by caregivers of women having mental illness is higher than that is expressed in the documented results of the present study.

The present study has implications for practice, administration, education and research. The analysis of burden of caregivers provide basic data required for making decisions, future research and generation of interventional strategies, all geared to promote holistic caring. Family interventional programs should be planned on the basis of a careful assessment of the burden experienced, coping strategies, interpersonal skills and social resources of each relative.

Mental illness and physical illness has a larger impact not only on the individual, but also on families and communities. Individuals not only suffer from the symptoms of the illness, but they are unable to participate in work and leisure activities often not only as a result of disability, but also because of the stigma and discrimination. There is a need to modify the current structure of organisation of current service delivery where specialist mental health nurse has limited role and responsibility of psycho- educational intervention. New positions have to be created for mental health specialist nurses, who is at present does not exist in the system at various levels of hospital and community settings.

Table 1. Clinical characteristics of mentally ill women Diagnostic distribution

Diagnosis of Group 1	Group 1 N=65	
	N	%
PSYCHOTIC GROUP	35	53.8
Schizophrenia	17	26.2
Major depressive disorder with psychotic features	7	10.8
Bipolar I disorder, most recent episode manic	5	7.7
Bipolar I disorder, single mania episode	3	6.0
Brief psychotic disorder	3	4.6
NON-PSYCHOTIC GROUP	30	46.2
Generalised anxiety disorder	10	15.4
Major depressive disorder without psychotic features	9	13.8
Conversion disorder	6	9.2
Obsessive compulsive disorder	3	6.0
Dissociative disorder	2	3.1

Table 2. Clinical characteristics of physically ill women

Diagnostic distribution		
Diagnosis of Physical illness	**Group 2 N=50**	
	N	%
Menorrhagia	12	24.0
Fibroid Uterus	11	22.0
Vaginitis	8	16.0
Dysfunctional Uterine bleeding	5	10.0
Dysmenorrhoea	5	10.0
Ovarian cyst	2	4.0
Ectopic Pregnancy	2	4.0
Pelvic inflammatory disease	2	4.0
Vaginal cyst	1	2.0
Cervicitis	1	2.0
Infertility	1	2.0

Table 3. Comparison of the Burden of Caregivers of mentally and physically ill women

Table 3: Comparison of the Burden of Caregivers						
Variable	**Group 1 N=65**		**Group 2 N=50**		**Z**	**P**
	Mean	SD	Mean	SD		
Physical & Mental Health	12.23	3.36	9.28	2.18	-4.72	0.000
External Support	10.44	3.26	7.62	2.91	-4.06	0.000
Caregiver routine	9.58	2.65	7.30	1.24	-4.74	0.000
Support of Patient	7.87	2.13	6.98	1.22	-2.84	0.005
Taking responsibility	8.55	2.12	7.80	2.07	-2.07	0.038
Other relations	5.55	1.85	4.78	1.56	-2.15	0.031
Patient's Behaviour	8.10	2.22	6.66	1.96	-3.43	0.001
Caregiver strategy	7.92	2.38	6.14	1.37	-4.29	0.000
Total Burden Score	70.27	15.68	56.56	6.70	-5.43	0.000

Table 4. Comparison of the age of onset and duration of illness between mentally and physically ill women

Table 4: Comparison of the sample: Age of onset and duration of illness							
Variable	**Group 1 N=65**		**Group 2 N=50**		**t**	**df**	**P**
	Mean	SD	Mean	SD			
Age of onset (years)	27.03	7.15	28.72	6.72	-1.28	113	0.20
Duration of illness (month)	41.00	41.72	9.76	7.33	5.22	113	0.00

Health professionals should identify such centres in their locality and refer patients to those centres for counselling so to alleviate the burden of carers. The concepts of burden are to be incorporated in to the undergraduate curriculum of health professionals training program, to sensitize future professionals in this area. Administrators of mental health services should be aware of the needs of the carers of patients having long term illness and formulate policies which enforce mental health professionals to include psychosocial interventions in their day to-day interventional activities with the patients and caregivers.

Conclusion

In summary, the present study has shown that there is a significant amount of burden experienced by caregivers of women having mental illness compare to physical illness. However the study has limitations of only women and small sample size. Future studies should be replicated on a larger sample, and both male and female should be involved. This study will provide information on the burden of care in women with mental illness and women with physical illness (gynaecological illness).

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