ORIGINAL ARTICLE

FEMALES WITH SCHIZOPHRENIA AND TROUBLES OF CAREGIVERS

Upendra Singh[1], Sweta[2], Praful Kapse[3], Vikas R. Sharma[4], Bhupendra Singh[4]

[1]DMHP Rohtas, (District Hospital, SASARAM) Bihar, India.
[2]Nayi Subah Institute of Mental Health, Varanasi, U.P., India
[3]Development Officer, Mental Health Initiative, Health Portfolio, SRTT & NRTT
[4]Institute of Mental Health, Pt. B.D. Sharma University of Health Sciences, Rohtak

ABSTRACT

Background : The concept of burden shares characteristics with that of social performance, existence of burden indicates the breakdown of the reciprocal arrangements that people maintain in their relationship such that one person is doing more than his fair share. Mental health and related services are still a source of stigma and frequently cause important issues for the caregivers and patients as well.

Aim : To assess the perceived family burden, depression, anxiety and stress among the caregivers of married and unmarried female patients with schizophrenia.

Methodology : 30 unmarried and 30 married female schizophrenia patients were recruited from Ranchi Institute of Neuro-Psychiatry and Allied Sciences (RINPAS) OPD and mental health stigma scale;depression, anxiety and stress scale; and perceived burden inventory were administered on their care givers.

Result : High level of Family burden was found in care givers of married patients but at the same time caregivers of unmarried patients living with psychosocial distress. High level of Depression, Anxiety and Stress were present in the caregivers of unmarried female patients.

Conclusion : The caregivers of married female schizophrenia patients perceived significantly higher burden in comparison to caregivers of unmarried female schizophrenia patients, whereas the latter group had significantly higher levels of depression, anxiety and stress.

Keywords : Burden, Caregiver, Female, Schizophrenia

INTRODUCTION

The World health report 1998 states that women's mental health is inextricably linked to their status in society[1]. It benefits with equality and suffers with discrimination. Women with severe mental illness frequently lack access to treatment setting, especially in low income countries where mental health facilitiesare scarce. Review article by Thara and Kamat[2] reports that human rights violations of female patients with severe mental illness are on rise. In the present perspective, it is now well recognized fact that mental illnesses, and their impact on society

Address for correspondence :
Bhupendra Singh, Assistant Professor, Department of Psychiatric Social Work, Institute of Mental Health, Pt. B.D. Sharma University of Health Sciences, Rohtak, Haryana, India
E-mail : 33bhupendrasingh @gmail.com

are increasing day by day globally, including India. Role of family becomes more important when the illness is chronic. The adverse effect of chronic illness on families is very significant and vice-versa for the quality of life, social support and service utilization for the persons with mental illness and the caregivers as well. The impact of mental illness is seen in family relationships and family dynamics including the role and functioning, decision making process and communication etc.

Severe mental illness in a family member can lead to varied responses including care burden, fear and embarrassment about illness, uncertainty about the course of disease, lack of social support, and stigma[3]. The caregivers have to deal with patient's symptoms and help the patient in activities of daily living[4].

Schizophrenia is a severe mental illness that takes a toll not only on the person who suffers from it, but also on caregivers and family members, leading to high levels of distress and burden of care[5]. Family members frequently experience a range of difficulties that include grief over losses experienced by the patient, shock and doubt over witnessing bizarre symptoms in a loved one, difficulties accessing treatment facilities, disruptions within the family due to the illness and needs of caring, financial burden caused by lack of time for work and unreimbursed medical expenses, limited leisure and social activities, and feelings of social stigma[6].

Nowadays, due to the fast pace of life, psychiatric illness has become a significant issue not only in India, but all over the world and the impact of such problems is well recognized. Previous studies show that care givers' perspectives are different for married and unmarried female psychiatric patients[7],[8]. Psychiatric disorders affect daily activities and personal life of caregivers and they face many problems due to psychiatric disorders of the family members. Family response to having a family member with mental illness include care burden, fear and embarrassment about illness signs and symptoms, uncertainty about course of the disease, lack of social support and these may manifest in the form of depression, anxiety and stress. Caregivers face several stressors including financial problems, disrupted family structure, physical health demands and many others[9]. In the concept of joint family in India, care for family members with incapability is an obligation and never considered a burden. However, family concepts are changing and the cohesion between the family members has weakened and this has createda lack of time sensitivity and social support. However, all caregivers don't perceive the same burden as it varies according to the family support, cultural beliefs and coping strategies.

The term "family burden" can be defined as the extent of suffering experienced by the family of a psychiatric patient due to various problems encountered with regard to financial conditions, routine, family interaction, leisure and physical and mental health of other members of the family caused by the illness of the psychiatric patients[10]. The possible areas of burden are effect on work or employment, effect on social life and leisure, physical health; effect on emotional/mental health, effect on finance, effect on schooling education, effect on children and effect on interaction with outside family. Gopinath & Rao[11] noted that due to the rapid industrialization and urbanization and subsequent changes in the family structure and role, care for psychiatric patients imposes a significant burden on the families in developing countries like India. Previous research has documented that up to 83% of the friends and family members of people diagnosed with Schizophrenia experience considerable financial, emotional and practical burdens[12]. This may not be only in sharing tasks, but also restricts a person's relationship with the society[13]. The physical and mental health condition of the primary family caregiver of schizophrenia patients was the most important factor determining the caregiver burden level[14].

AIM OF THE STUDY

The aim of the study was to assess the stigma, family burden and depression, anxiety and stress among caregivers of married and unmarried female schizophrenia patients.

METHODOLOGY

The study followed cross-sectional hospital based descriptive research design conducted at out-patient department of Ranchi Institute of Neuro-Psychiatry and Allied Sciences (RINPAS), Kanke, Ranchi from January 2015 to September 2017. Total 60 participants (30 married and 30 unmarried female schizophrenia patients) matching study criteria were selected through purposive sampling technique as primary sample and their primary caregivers were recruited as study sample. Ethical permission was obtained from Institutional research committee. Written informed consent was obtained from the participants. Basic socio demographic details were gathered in semi-structured datasheet, difficulties of care were assessed by Family Burden Interview Schedule[15]; and Hindi Adaptation of Depression, Anxiety and Stress Scale 16 was administered to check depression, anxiety and stress among caregivers of the primary participants.

INCLUSION CRITERIA

- Primary Caregivers of female schizophrenia patients who were diagnosed according to International Classification of Diseases 1017
- Caregivers aged 25 to 50 years.
- Caregivers involved in care giving for at least last 6 months.

EXCLUSION CRITERIA

- More than one family member with mental illness
- Caregiver/other family member with history of severe physical illness.
- Caregivers who opt professional (institutional) care giving facilities for the patients

RESULTS

Patients' mean age was 26.7 (+8.25) years. Regarding educational qualification of the patients, 35% of the participants were illiterate, 18% participants are educated upto primary standard and 31% of them were acquiring degree of high school. Forty three percent of them were housewives, 23% working (self employed labour) and 20% were students.

In the study sample of caregivers, the mean age was 41.4 (+12.9) years and 65% were male and 35% of them were female. Regarding educational qualifications, 28% were illiterate, 35% were primary educated, 15% were educated up to 8th, 2% educated up to high School and 20 % of them had post graduation qualification.Coming to the relationship of caregivers with the patients, 48% of the caregivers were parents to the patients, followed by 30% being husband or in laws, 20% being siblings and only 2% were children. 58% of the participants belonged to nuclear family and 42% were from joint family. Three forth (75%) of the participants were from rural background and 73% were Hindus and 17% participants followedSarana religion. Regarding the caste, majority (55%) were from other backward classes followed by general 23% and 22% schedule caste/schedule tribe.

Table No. 1 : Burden among Caregivers of Married and Unmarried Schizophrenia Patients

Variables	Married (n=30)	Unmarried (n=30)	t	P
Financial Burden	6.43±1.61	4.36±2.29	4.034	.000
Daily Routine Burden	6.33±2.79	4.73±2.42	2.378	.021
Leisure Burden	3.26±2.09	3.50±1.68	0.478	.634
Communication Burden	4.13±2.44	2.90±2.10	2.693	.041
Physical Health Burden	1.10±1.21	0.30±0.74	3.125	.003
Mental Health Burden	1.70±1.02	1.30±0.74	1.725	.089
Total Burden	22.96±6.35	17.10±6.24	3.607	.001

Table 1 shows the level of caregiver burden and comparison between the married and unmarried female schizophrenia patients. Burden is high among the caregivers of married female patients in every domain of the family burden interview schedule. It is highly significant in area of financial and total or overall burden, also significant in daily routine, communication and physical health.

Table 2 : Depression, Anxiety and Stress among Caregivers of Married and Unmarried Female Schizophrenia Patients

Variables	Married (n=30)	Unmarried (n=30)	t	P
Depression	4.96±1.67	7.63±3.38	3.866	.000
Anxiety	4.53±1.97	6.40±2.73	3.028	.004
Stress	5.70±2.19	7.36±2.87	2.524	.014

Table 2 depicts that depression is significantly (P<0.01) high in the caregivers of unmarried schizophrenia patients. Similarly, anxiety and stress were also high in the caregivers of unmarried females with schizophrenia in comparison to caregivers of married females with schizophrenia.

DISCUSSION

A woman plays a very special role in the family. Several women empowerment programs are implemented nationally by various government and non-government organizations but in our culture, woman are not accepted as a source of power and they are never considered an independent unit of society. It is believed that a female is primary responsibility of her parents and in conditions of ill health, her parents have to take care of her. It is a kind of discrimination which is shown by the in laws towards a female. This discrimination multiplies when a female is diagnosed with a severe mental illness like schizophrenia. It frequently happens that a woman is sent back to her maternal house for the treatment and proper care. This paper will give a brief overview of caregivers' perspective towards married and unmarried females suffering from schizophrenia. Findings of the present study show that the family burden for the caregiversof both married and unmarried females with schizophrenia is quite high. Study by Ohaeri also reported that the relatives of patients with psychotic symptoms bear a greater burden[18]. Review from the prior findings shows chronic course of schizophrenia has a greater burden[19,20]. Similarly, families of patients with chronic illness with severe loss of insight experienced higher burden[21]. Veltmanet al[22] also reported high level of subjective care burden. Moreover, subjective burden mediates stress reaction in caregivers to the burden of care and subjective burden as equal to stress[23]. In the present study,the total burden among the caregivers of married female schizophreniapatients was significantly higher than that in care providers of unmarried female schizophrenia patients.

We also found that financial burden is high among the caregivers of married female schizophrenia patients. This may be due to the scarcity of money for treatment expenses and refusal of in laws to take any responsibility for the treatment of the patients. Daily routine is also affected in both groups of caregivers, but the impact is higher in the caregivers of married patients. It is mainly due to poor understanding of illness and social stigma and most importantly, it is due to rejection from husband and in laws. Mental health burden and leisure burden is higher in caregivers of married female patients in comparison to the unmarried patients. A previous study also found that embarrassment is one of the main emotional reactions reported both in patients and caregivers of schizophrenia[24].

In Indian culture, marriage of a woman is sole responsibility of her parents and any problem related to the marriage is considered a failure of family members. Poor prognosis, treatment acceptance and prejudice towards mental illness create taboo against it and this becomes a hurdle for the marriage of female patients. During the current study, many of the parents shared their concerns about the marriage of the patient and other related worries. Our study also showed that in spite of the lower levels of burden, caregivers of unmarried patients reported high levels of depression whichcan be attributed tothe fear of future; high levels of anxiety which can be explained by worries about the marriage and better management of remaining life and high level of stresswhichmay bebecause of poor social acceptance of persons with mental illness. The stress of the interactions with the afflicted family member as well as the distress associated with the illness, places an incredible amount of strain on the day-to-day functioning of that family[25]. The findings of our study emphasize that poor acceptance of social relationship with patients is the key factor behind the high rates of depression, anxiety and stress among the caregivers of unmarried female with schizophrenia.

CONCLUSION

The burden of care in schizophrenia is quite high around the globe including India. Mental health stigma is also a target of researchers and clinicians worldwide as it worsens the life of patients and their caregivers. Knowledge, understanding and acceptance will have positive impact not only on the mental health of schizophrenia patients, but also on their caregivers.

REFERENCES

1. World Health Organization. The World health report : 1998 : Life in the 21st century: a vision for all : executive summary.
2. Thara R, Kamath S. Women and schizophrenia. Indian journal of psychiatry. 2015 Jul; 57 (Suppl 2) : S 246.
3. Talwar P, Matheiken ST. Caregivers in schizophrenia : A cross cultural perspective. Indian journal of psychological medicine. 2010 Jan; 32 (1) :29.
4. Lueboonthavatchai P, Lueboonthavatchai O. Quality of life and correlated health status and social support of schizophrenic patients' caregivers. Journal of the Medical Association of Thailand, Chotmaihetthangphaet. 2006 Sep; 89 : S 13-9.
5. Michelle S. Friedman-Yakoobian. Mamani A.W. and Kim T. Mueser. Predictors of distress and hope in relatives of individuals with schizophrenia. The Israel journal of psychiatry and related sciences. 2009 Apr 1; 46 (2) : 130.
6. Marsh DT, Johnson DL. The family experience of mental illness : implications for intervention. Professional Psychology : research and practice. 1997 Jun; 28 (3) : 229.
7. Emanuel EJ, Fairclough DL, Slutsman J, Alpert H, Baldwin D, Emanuel LL. Assistance from family members, friends, paid care givers, and volunteers in the care of terminally ill patients. New England Journal of Medicine. 1999 Sep 23; 341 (13) : 956-63.
8. Kim Y, Baker F, Spillers RL. Cancer caregivers' quality of life : effects of gender, relationship, and appraisal. Journal of pain and symptom management. 2007 Sep 1; 34 (3) : 294-304.
9. Nehra R, Chakrabarti S, Kulhara P, Sharma R. Caregiver - coping in bipolar disorder and schizophrenia. Social Psychiatry and Psychiatric Epidemiology. 2005 Apr 24; 40 (4) : 329 - 36.
10. Chakrabarti S, Raj L, Kulhara P, Avasthi A, Verma SK. Comparison of the extent and pattern of family burden in affective disorders and schizophrenia. Indian journal of psychiatry. 1995 Jul; 37 (3) : 105.
11. Gopinath PS, Rao K. Rehabilitation in psychiatry : An overview. Indian journal of psychiatry. 1994 Apr ; 36 (2) : 49.
12. Magliano L, Marasco C, Fiorillo A, Malangone C, Guarneri M, Maj M. The impact of professional and social network support on the burden of families of patients with schizophrenia in Italy. ActaPsychiatrica Scandinavica. 2002 Oct 1; 106 (4) : 291-8.
13. Fadden G, Bebbington P, Kuipers L. The burden of care : the impact of functional psychiatric illness on the patient's family. The British Journal of Psychiatry. 1987 Mar 1; 150 (3) : 285-92.
14. Hou SY, Ke CL, Su YC, Lung FW, Huang CJ. Exploring the burden of the primary family caregivers of schizophrenia patients in Taiwan. Psychiatry and clinical neurosciences. 2008 Oct 1; 62 (5) : 508-14.
15. Pai S, Kapur RL. The burden on the family of a psychiatric patient : development of an interview schedule. The British Journal of Psychiatry. 1981 Apr 1; 138 (4) : 332-5.
16. Singh B, Prabhuappa KP, Eqbal S, Singh AR. Depression, anxiety and stress scale: Reliability and validity of Hindi adaptation. International Journal of Education and Management Studies. 2013 Dec 1; 3 (4) :446.
17. Ohaeri JU. Caregiver burden and psychotic patients' perception of social support in a Nigerian setting. Social Psychiatry and Psychiatric Epidemiology. 2001 Apr 24; 36 (2) : 86-93.
18. World Health Organization. The ICD-10 classification of mental and behavioural disorders : clinical descriptions and diagnostic guidelines. World Health Organization; 1992.
19. Giel R, Arango MV, Babikir AH, Bonifacio M, Climent CE, Harding TW, Ibrahim HH, Ladrido Ignacio L, Murthy RS, Wig NN. The burden of mental illness on the family. Acta Psychiatrica Scandinavica. 1983 Sep 1; 68 (3) : 186-201.
20. Li J, Lambert CE, Lambert VA. Predictors of family caregivers' burden and quality of life when providing care for a family member with schizophrenia in the People's Republic of China. Nursing & Health Sciences. 2007 Sep 1; 9 (3) : 192-8.
21. Scazufca M, Kuipers E. Links between expressed emotion and burden of care in relatives of patients with schizophrenia. The British journal of psychiatry. 1996 May; 168 (5) : 580-7.

22. Veltman A, Cameron JI, Stewart DE. The experience of providing care to relatives with chronic mental illness. The Journal of Nervous and Mental Disease. 2002 Feb 1; 190 (2) : 108-14.

23. Chang KH, Horrocks S. Lived experiences of family caregivers of mentally ill relatives. Journal of Advanced Nursing. 2006 Feb 1; 53 (4) : 435-43.

24. Lasebikan VO, Ayinde OO. Family burden in caregivers of schizophrenia patients : Prevalence and socio-demographic correlates. Indian journal of psychological medicine. 2013 Jan; 35 (1) : 60.

25. Pollio DE, North CS, Reid DL, Miletic MM, McClendon JR. Living with severe mental illness — what families and friends must know : evaluation of a one-day psychoeducation workshop. Social Work. 2006 Jan 1; 51 (1) : 31-8.