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Burden of Care and Depression in Caregivers of Patients with Schizophrenia

Mubeen Taj[1], Maithreyi Poguri[2], Glady Mariayana[3], Sujitha Jebarose[4], Christina Mary Paul[5]

[1]ACS Medical college and hospital, Chennai, India
[2]ACS medical college and hospital, Chennai, India
[3]Dr MGR Educational and research institute, Chennai, India
[4]Dr MGR Educational and research Institute, Chennai, India
[5]Indra medical college and Hospital, Chennai, India

ABSTRACT

Background: Schizophrenia, a chronic psychiatric disorder affecting all major domains of a patient's life, leads to significant disability. Since the deinstitutionalization policy, the onus of care is on families especially the primary caregiver who experiences physical and emotional burden. Depression among caregivers has been estimated to be higher than the general population. This cross-sectional study aimed to assess burden of care and depression in primary caregivers and associated caregiver variables.

Methods: 75 consenting primary caregivers of patients with ICD-10 diagnosis of schizophrenia were assessed for burden of care and depression using the Burden Assessment Schedule and the Patient Health Questionnaire - 9 after collecting socio-demographic and caregiving details.

Results: All the caregivers, 49 females and 26 males, had moderate to high levels of burden with a majority having moderate to severe levels of depression. Spouses (p=0.0038), older caregivers (p=0.01) and those with lower educational levels (p=0.01) experienced more burden. There was a significant positive correlation between burden of care and depression (p=0.000).

Conclusion: In one of India's largest metropolitan cities, though psychiatric services are easily available, caregivers continue to feel burdened and depressed. This can impact not just the caregiver but also care being provided to the patient and illness outcome.

Key words: Schizophrenia, Disability, Caregiver, Burden, Depression

BACKGROUND

Schizophrenia is a severe mental disorder affecting nearly 20 million people globally[1] and runs a chronic course with exacerbations and remissions, each relapse being followed by a further decline in the patient's baseline functioning.[2,3] It is still ranked among the top 10 leading causes of disease-related disability world-wide.[4,5] With antipsychotic medications, over three fourths of the patients show improvement of positive psychotic symptoms but this does not guarantee an improvement in critical areas of day-to-day functioning such as maintaining employment, social relationships and living independently, as the medications rarely impact the cognitive deficits or negative symptoms.[6] It is also associated with frequent psychiatric and medical comorbidities and life expectancy is on an average 20 years less than the general population posing a serious challenge to health systems particularly in low-income and middle-income countries.[6,7] The economic burden associated with schizophrenia is disproportionately high relative to other chronic mental and physical health conditions reflecting the chronic and debilitating nature of the disease resulting in 'direct' costs of health care as well as 'indirect' costs due to reductions in ability to achieve real-world functional outcomes.[8,9] Stigma as-

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Correspondence: Dr. Mubeen Taj (Email: mubeenarshad05@gmail.com)

sociated with schizophrenia contributes to discrimination thereby limiting access to general health care, education, housing and employment.[1] India being a developing country with a population of 1.3 billion, 197.3 million were diagnosed with mental disorders and their contribution to total disease burden is said to have doubled between 1990 and 2017. Of the 197.3 million, schizophrenia was the diagnosis in 3.5 million people.[7]

Burden of care and depression in caregivers

As patients with schizophrenia struggle to maintain social relationships, sustain employment and live independently, they need significant support in their daily life. [6] In India, the family is a major source of support for the mentally ill and the majority of people with schizophrenia stay with their families.[10,11] Caring for persons with severe mental disorders can be a devastating stressor in any family regardless of the strengths of the family and resources available for coping. Although the entire family as a unit provides considerable support, the responsibility of caring is often shouldered by one 'primary care giver' who experiences physical and emotional burden.[12] The needs of the caregivers can be multiple, varying across cultures.[10] Often caregivers are less aware of the psychiatric nature of the illness, so their educational needs include gaining information about warning signs of a relapse, effects of medication and ways of coping with the patient's behavior. Disruption in family routine was an area in which burden was experienced and disruptions of family interactions was another significant aspect of burden besides financial burden.[9] Caregiver burden is exacerbated by issues of illiteracy and poverty. Many a time the caregivers' efforts go unrecognized.[11]

In India, caregivers of patients with schizophrenia have major role to play monitoring the daily medication, accompanying the patients for doctor reviews, monitoring Activities of Daily living (ADL), cognitive retraining, vocational and social skills training of the patients. This is not only because of the close family ties that that exist in these traditional societies but also because of the lack of mental health and rehab professionals to deliver these services.[11]

The complex and varied aspects of caregiving can strain even the most resourceful person. Given the nature of the illness and the prolonged process of providing care, the caregivers are often unable to fulfil their own aspirations at a personal, social, occupational level.[13] This may lead to psychological distress and it is not unusual for caregivers to develop depression as a result of the constant demands they face while providing care, with depression in caregivers of patients with mental illness estimated to be two times higher than the general population.[14] Depression can affect their routine activities, work performance, social interaction, their physical well-being and their quality of life. This may have a cascading effect on the care being provided to the patient with schizophrenia and the outcome of the illness.

In a developing country like India with just 0.75 psychiatrists per 100,000 population[15] and where the primary focus is on the patient and chiefly symptom control, the needs of the caregiver are mostly unmet.

With this background this study was conducted to assess burden of care and depression in primary caregivers of patients with schizophrenia and caregiver variables associated with it.

METHODS

In this cross-sectional study, 75 caregivers of patients with schizophrenia, accompanying the patients to the out-patient clinical services at Schizophrenia Research Foundation (SCARF), a mental health center and non-profit organization based in Chennai, a metropolitan city in south India, offering a multidisciplinary comprehensive range of psychiatric care and rehabilitation services, fulfilling the necessary criteria and consenting to participate in the study were included. This center caters to about 10-12 new patients and about 70-80 patients who come for a review, per day. Of these about 30-40% are patients with schizophrenia.

Approval for the study was obtained from the Institutional Ethics Committee of A.C.S. Medical College, Dr MGR Educational and Research Institute, Chennai. Data was collected between October and November 2018. The primary care giver was defined as the member of the family who was most involved with the care of the patient with an ICD-10 diagnosis of schizophrenia. Both patient and caregiver were older than 18. Primary care givers who were away from the patient at least for a month in the past three months were excluded. Those caregivers with a prior diagnosis of a psychiatric disorder were also excluded from the study. The study subjects were administered the following:

(1) A proforma to collect sociodemographic details and other information regarding relationship to the patient, frequency of contact with the patient and duration of care.

(2) Burden Assessment Schedule [BAS]: The caregiver burden was assessed using the BAS[12], developed by SCARF. It is a structured instrument comprising of 40 items and each item is rated on a 3-point scale (1: not at all; 2:to some extent; 3: very much). Based on the total score the level of burden was further categorized as low (1-40), moderate (41-80) and high (81-120).

(3) Patient Health Questionnaire [PHQ-9]: This structured 9 item questionnaire was used to assess depression. PHQ-9[16] score can range from 0 to 27. Each of the 9 items are scored from 0 (not at all) to 3 (nearly every day). A score of 10-14 on this questionnaire indicates moderate depression, score of

15-19 indicates moderately severe depression while a score of 20-27 indicates severe depression.

The data so collected was analysed using SPSS. For sociodemographic variables of the study subjects and the patient care descriptive data percentages were calculated. Chi-square test was used to study the association between BAS scores and caregiver variables and also to study the association between PHQ-9 scores and caregiver variables. The association between burden of care and depression was studied using Pearson's correlation. The Mantel-Haenszel test was used for odds ratio.

OBSERVATIONS

A total of 75 caregivers participated in the study of which 49 were female and 26 were male. 42 (56%) were more than 45 years old. A majority, 62 of the care givers were married (82.7%). Only 24 (32%) had college level education while 40 (53.3%) were educated below high school level. 37 (49.3%) of the caregivers were employed (Table 1).

Table 1: Socio-demographic profile of the caregivers (N=75)

Variable	Caregiver (%)	95% CI of %
Age		
≤ 45 years	33 (44)	32.6 – 55.9
> 45 years	42 (56)	44.1 – 67.4
Gender		
Male	26 (34.7)	24 – 46.5
Female	49 (65.3)	53.5 – 76
Marital Status		
Single	9 (12)	5.6 – 21.6
Married	62 (82.7)	72.2 – 90.4
Divorced/Separated	1 (1.3)	0.03 – 7.21
Widow/Widower	3 (4)	0.8 – 11.3
Education Status		
Primary & Middle School	40 (53.3)	41.5 – 65
Secondary School	11 (14.7)	7.6 – 24.7
Graduate and above	24 (32)	21.7 – 43.8
Employment status		
Employed	37 (49.3)	37.6 – 61.1
Unemployed	38 (50.7)	38.9 – 62.4

Table 2: Patient care details of the caregivers (N=75)

Variable	Caregiver (%)
Relationship to the patient	
Parent	25 (33.3)
Spouse	22 (29.3)
Children	17 (22.7)
Sibling	8 (10.7)
Other Relatives	3 (4)
Accommodation	
Lives with patient	64 (85.3)
Does not live with the patient	11 (14.7)
Frequency of contact with the patient	
Daily	72 (96)
Less Frequent	3 (4)
Years of provision of care	
< 5 years	25 (33.3)
≥ 5 years	50 (66.7)

The 95% C.I. for the socio-demographic variables was calculated for generalizability of the results within the range of the 95% C.I.

Total 25 (33.3%) of the caregivers were parents of the patients with schizophrenia while 22 (29.3%) were spouses of the patients. A majority, 64 of the caregivers were living with the patient (85.3%) and 72 (95%) of them were in contact with the patient on a daily basis. 50 (66.7%) of the caregivers had been providing care for 5 or more years (Table 2).

All the primary care givers (N=75) had moderate to high levels of burden based on the Burden Assessment Schedule scores with 40 (53.3%) of the caregivers having moderate levels and 35 (46.7%) of the care givers having high levels of burden (Figure 1).

Based on the PHQ-9 scores, 66.6% of the caregivers had moderate to moderately severe depression while 6 (8%) had severe depression (Figure 2).

There was a significant correlation between the age of the caregiver and level of burden, with older caregivers experiencing more burden. There was also a significant correlation between the level of education and burden, caregivers with lower educational levels experiencing more burden. Spouses of the patients with schizophrenia experienced significantly more burden compared to other relatives (Table 3).

Based on the odds ratio, the burden of care though not significant, was more in women caregivers, caregivers who were married, those who were employed, less than 5 years of caregiving and those in daily contact with the patient.

Though not significant based on the odds ratio depression was more in older caregivers, women caregivers, those with lower education levels, employed, caregivers in daily contact with the patient and if the caregivers were spouses of the patients.

A highly significant positive correlation was seen between the level of burden and depression scores as seen in Table 5.

DISCUSSION

A majority, 49 of the caregivers in this study were females (65.3%). The concept of family burden being a 'gendered notion' with female relatives providing a major portion of caregiving has been observed in studies across cultures.[11,14,17,18]

Majority of the caregivers in this study were middle aged or older and were married. Majority of the caregivers had primary and middle school level education with nearly half of the caregivers being unemployed. A major portion of the caregivers were either parents or spouses of patients with schizophrenia and were living with the patient. Almost all the caregivers 72 (96%) were in contact with the patient on a daily basis.

Table 3: Association between BAS Score and caregiver variables

Variable	Subjects with Severe burden (n= 35) (%)	Subjects with Moderate burden (n= 40) (%)	Odds ratio (95% C.I)	p-value
Age				
>45 years (42)	25 (71.4)	17 (42.5)	3.4 (1.29 – 8.9)	0.01*
≤45 years (33)	10 (28.6)	23 (57.5)	1.00	
Gender				
Female (49)	23 (65.7)	26 (65)	1.03 (0.40 – 2.68)	0.95
Male (26)	12 (34.3)	14 (35)	1.00	
Marital status				
Currently married (62)	31 (88.6)	31 (77.5)	2.25 (0.63 – 8.08)	0.33
Single/ separated/ widowed (13)	4 (11.4)	9 (22.5)	1.00	
Educational Status				
Below high school (40)	24 (68.6)	16 (40)	3.27 (1.26 – 8.49)	0.01*
High school and above (35)	11 (31.4)	24 (60)	1.00	
Employment Status				
Employed (37)	18 (51.4)	19 (47.5)	1.17 (0.47 – 2.90)	0.74
Unemployed (38)	17 (48.6)	21 (52.5)	1.00	
Duration of provision of care				
< 5 years (25)	14 (40)	11 (27.5)	1.76 (0.67 – 4.61)	0.26
≥ 5 years (50)	21 (60)	29 (72.5)	1.00	
Accommodation				
Does not Live with the patient (11)	8 (22.9)	3 (7.5)	3.65 (0.89 – 15.07)	0.12
Lives with the patient (64)	27 (77.1)	37 (92.5)	1.00	
Frequency of contact with patient				
Daily (72)	34 (97.1)	38 (95)	1.79 (0.15 – 20.63)	1.00
Less frequent (3)	1 (2.9)	2 (5)	1.00	
Relationship to the patient				
Spouse (22)	16 (45.7)	6 (15)	4.77 (1.60 – 14.24)	0.0038*
Other relations (53)	19 (54.3)	34 (85)	1.00	

* - Statistically significant

Table 4: Association between PHQ- 9 Score and caregiver variables

Grouping of Variable (Number)	Subjects with moderately severe and severe of depression (n=31) (%)	Subjects with none, mild and moderate levels of depression (n=44) (%)	Odds ratio (95% C.I)	p-value
Age				
>45 years (42)	20 (64.5)	22 (50)	1.82 (0.71 – 4.67)	0.215
≤ 45 years (33)	11 (35.5)	22 (50)	1.00	
Gender				
Female (49)	22 (71)	27 (61.4)	1.54 (0.57 – 4.12)	0.39
Male (26)	9 (29)	17 (38.6)	1.00	
Marital status				
Single/ separated/ widowed (13)	8 (25.8)	5 (11.4)	2.71 (0.79 – 9.29)	0.18
Currently married (62)	23 (74.2)	39 (88.6)	1.00	
Educational Status				
Below high school (40)	18 (58.1)	22 (50)	1.38 (0.55 – 3.50)	0.49
High school and above (35)	13 (41.9)	22 (50)	1.00	
Employment Status				
Employed (37)	17 (54.8)	20 (45.5)	1.46 (0.58 – 3.67)	0.43
Unemployed (38)	14 (45.2)	24 (54.5)	1.00	
Duration of provision of care				
≥ 5 years (50)	22 (71)	28 (63.6)	1.40 (0.52 – 3.76)	0.51
< 5 years (25)	9 (29)	16 (36.4)	1.00	
Accommodation				
Doesn’t Live with the patient (11)	5 (16.1)	6 (13.6)	1.22 (0.34 – 4.41)	1.00
Lives with the patient (64)	26 (83.9)	38 (86.4)	1.00	
Frequency of contact with patient				
Daily (72)	30 (96.8)	42 (95.5)	1.43 (0.12 – 16.49)	1.00
Less frequent (3)	1 (3.2)	2 (4.5)	1.00	
Relationship to the patient				
Spouse (22)	11 (35.5)	11 (25)	1.65 (0.60 – 4.50)	0.33
Other relations (53)	20 (64.5)	33 (75)	1.00	

* - Statistically significant

Table 5: Association between the BAS Score and the PHQ – 9 score

Sample size	Variable	Mean	Standard Deviation	Correlation Coefficient (r)	p - Value
75	BAS Score	78.8	10.6	1	0.000*
75	PHQ – 9 score	13.1	4.6	0.468	

* - Statistically significant

A majority of the caregivers were providing care for 5 years or more. Studies from India have shown that the vast majority of the people with severe mental disorders like schizophrenia, live with their family members who are required to provide care for extended periods of time [10,11] with families viewing care giving as their responsibility towards their relatives with mental illness [10] and most refusing to consider the idea if separation involving sending the ill member to an institution or home.[12] A study from the same metropolitan city in 1985-86, showed nearly one-third of patients with schizophrenia were untreated and were more severely ill for a long duration with severe disability, living with extended/joint type family units with family members compensating for lack of participation by the patient.[19]

A patient's baseline functioning deteriorates further following each relapse with the classic course of schizophrenia being one of relapses and remissions. [2] Patients despite a reduction or elimination of positive symptoms with medication, continue to have difficulty in critical areas of day-to-day functioning such as personal care, social relationships, being gainfully employed and living independently thereby requiring significant support in their daily life. [2,6] Stigma being high, it contributes to discrimination and this in turn can limit access to general health care, education, housing as well as employment. [1] The failure to meet milestones with regard to social relationships, employment and independent living can bring about cyclical disability and poverty with majority of the patients needing disability compensation or becoming dependent on a relative for financial support over time. [6] Caregiving being an enormous task under these circumstances, the caregivers often seem unprepared for the longitudinal course and duration of this illness [13] with both rural and urban families experiencing equal burden in India.[20]

Taking into account the entire family as a unit, schizophrenia in one member, inevitably impacts the entire unit, with changes in the daily family routine as well as the roles and responsibilities of the family members. [21] The addition of the caregiving role to already existing roles can become stressful physically, psychologically and financially. [22] This negative impact on the family is referred to as burden. [17] Caregiving involves assuming unpaid and unanticipated responsibility for the patient with minimal psychological rewards of caring as the patient has difficulty in reciprocating due to the inherent nature of the illness, making caregiving burdensome. [13,23] Besides patients, the caregivers also face the issue of stigma and often find themselves ostracized by the society. [11,22] In urban India, with nuclear families rapidly displacing joint families and with more women seeking employment, caring for family member with schizophrenia is often shouldered by a single caregiver. [12] Caregivers are often unable to pursue their own interests and achieve their desires at a personal, occupational, familial and social level. [13] All the caregivers in this study had moderate to high levels of burden on the BAS.

On looking at the caregiver variables and burden in this study it was found that caregivers who are middle aged and older had higher burden. As they grow older, the caregivers may have physical health concerns of their own, difficulty taking the patient for regular reviews, supervising medication, helping the patient with personal care, financial constraints and the concern as to who will care for the patient after them. While some studies showed that age of the caregiver had no impact on burden [22] some others found that caregivers who are younger experienced greater burden [13,21] as they are more likely to have additional responsibilities of holding a job, caring for aged parents and raising children.

Lower educational levels of the care giver have been shown in several studies to be associated with greater burden. [21,22] In this study those care givers with primary or middle school level education were found to have significantly higher burden levels compared to those with higher education. Those who are better educated may have better access to resources and services for the patient and themselves, access information for a better understanding of the patient's illness. Education being linked to better employment opportunities may contribute by reducing the financial burden as well. Employment status of the caregiver had no significant bearing on burden in this study. Caregivers who are unemployed probably having to spend more time with the patient and on caregiving tasks and may also have financial strain having to provide for patient care and treatment. Caregivers who are employed have the dual responsibility of caring for the patient as well as handling the requirements of their job especially if it is a small or nuclear family.

In this study spouses of the patients with schizophrenia were found to have significantly higher burden than the other relatives as caregivers. Spouse caregivers reported greater emotional burden, experience difficulty having to balance multiple roles, raising children on their own, financial burden especially when the primary wage earner is the patient. [23,24] This indicates the need for specific interventions to address the needs of the spouses. Some studies found that if the caregiver was the adult son or daughter of the patient, the burden scores were significantly higher, possibly because they have a family of their own to care for besides their ailing parent.[21,23] While some others have reported that burden was experienced by both parents and spouses in their role as caregivers.[24] One study found that though parents and spouses reported moderately higher level of burden, siblings reported highest level of burden.[22]

In this study though not significant, women were found to experience more burden. Though some studies did not find significant gender differences,[21,22,25] some studies on spouses showed that females experienced greater burden as besides the domestic responsibilities the illness in the husbands creates extra financial, caring and social responsibilities for them.[26] Studies where majority of the caregivers were mothers, they carried more burden and studies with higher number of male caregivers have shown that caregiving seems to cause even more burden on males since this is not a role traditionally attributed to them.[21]

Though not significant this study found that the burden of care was more in the married caregivers. Burden scores of single caregivers were significantly higher than those of married caregivers in a study from Turkey while another from Nigeria reported increase in burden of caregiving in single or widowed caregivers due to greater impairment in family routines as well as financial difficulties.[21]

Being in contact with the patient on a daily basis showed an increase in burden in this study, though not significant. Winefield & Harvey (1994) reported that high contact was consistently associated with greater burden with the total number of areas of the caregiver's life affected by caregiving responsibilities being significantly related to the level of contact, as was the total amount of patient related caregiver stress and nearly half of the caregivers would prefer the patient to live somewhere supervised.[23] Cross cultural studies have shown that in developing countries attitudes towards mental illness are more tolerant.[17]

There was no significant difference with regard to duration of caregiving on caregiver burden in a study from India.[22] This study found that those who were caring for the patient for less than five years experienced more burden though the difference was not statistically significant. During the early years of caregiving, the caregiver has to come to terms with the diagnosis, having to deal with the behavioural disturbances due to the psychotic symptoms, stigma, hospitalizations due to relapses, disruptions in family routine and with increase in duration of caregiving they have to deal with the failure of the patients in meeting milestones in social relationships, employment and independent living brought on by the negative and cognitive symptoms, all contributing to burden.

Except for a small minority almost all the caregivers had mild to severe depression in this study with 41.3% having moderately severe to severe depression. Previous studies from India have shown 65% of the primary caregivers having mild to severe depression using the MADRS and 24% of the caregivers having moderate to severe scores on the PHQ-9 [13,27] while a study from Ethiopia reported depression in 19% of the caregivers. Though not significant, depression was found to be more in women caregivers, spouses of the patients, older caregivers, those with lower education levels, caregivers who were employed and those who were in daily contact with the patient. A highly significant association was noted between the burden levels and depression. Studies have shown that certain patient factors like severity of symptoms, length of time spent in hospitals, duration of illness, number of hospitalizations may increase family burden and depression [13,14]. Regarding caregiver characteristics studies have shown that higher education levels were negatively associated with depression in the middle-income countries [14,27]. With depression among caregivers of patients with mental illness being reported to be more than two times than the general population, this needs to be addressed appropriately as it not only affects the caregiver, it can increase care costs for both the patient and caregiver and can also impact on caregiving tasks thereby affecting the treatment process and outcome for the patient with schizophrenia.

Clinical Implications

With de-institutionalisation and the practice of community psychiatry , the role of caregivers in the treatment of a patient with a chronic and disabling disorder like schizophrenia, cannot be overemphasized. Despite experiencing significant burden, the family caregivers provide considerable support to the patients with schizophrenia. Despite there being research spanning over decades regarding caregivers, burden and depression among caregivers remains a matter of concern even in fairly resource rich city where both government and private treatment facilities are very much available, as seen in this study. In a developing country like India where there are few psychiatrists and even fewer psychologists and rehab professionals especially outside of the major cities, allievating the patient's symptoms continues to be the main focus in the treatment process and the caregiver's needs are rarely addressed. As part of the treatment process for patients with schizophrenia, effort needs to be made to understand the caregiver needs in a cultural context and develop specific interventions to try and reduce caregiver burden and promote their well-being.

LIMITATIONS

This study is limited by the small number of urban study subjects, also the patient variables associated with burden and depression in caregivers have not been studied. The data for this study was collected over a period of one month. Due to this short duration only 75 caregivers fulfilling study criteria and consenting for the study could be recruited.

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DECLARATION OF CONFLICTING INTERESTS

The authors declare that there is no conflict of interest.

REFERENCES

1. World Health Organisation: Home/ Newsroom/ Fact sheets/ Detail/ Schizophrenia. Available at: http://who.int/news-room/fact-sheets/detail/schizophrenia#
2. Sadock BJ, Sadock VA, Ruiz P. Schizophrenia spectrum and other psychotic disorders. Synopsis of Psychiatry. 11th ed India: Wolters Kluwer; 2015.
3. Tandon R, Nasrallah HA, Keshavan MS. Schizophrenia, "Just the facts" Clinical features and conceptualization. Schizophrenia Res 2009; 110: 1-23.
4. Global, regional and national incidence, prevalence and years lived with disability for 328 diseases and injuries for 195 countries, 1990-2016: A systematic analysis for the Global Burden of Disease Study 2016. Lancet 2017; 390(10100): 1211-59.
5. Tandon R, Keshavan MS, Nasrallah HA. Schizophrenia, "Just the Facts": What we know in 2008, Part 1: Overview. Schizophrenia Res 2008; 100: 4-9.
6. Harvey PD, Strassnig MT, Silberstein J. Prediction of disability in schizophrenia: Symptoms, cognition and self-assessment. J Exp Psychopathol 2019; 10(3): 1-20.
7. India State-Level Disease Burden Initiative Mental Disorders Collaborators. The Burden of mental disorders across the states of India: The Global Burden of Disease Study 1990-2017. Lancet Psychiatry 2020; 7(2): 148-61.
8. Desai PR, Lawson KA, Barner JC, Rascati KL. Estimating the direct and indirect costs for community-dwelling patients with schizophrenia. J Pharm Health Serv Res 2013; 4(4): 187-94.
9. 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 J Psychiatry 1995; 87(3): 105-12.
10. 10. Jagannathan A, Hamza A, Thirthalli J, Hariprasad VR, Nagendra HR, Gangadhar BN. A qualitative study on the needs of caregivers of in-patients with schizophrenia in India. Int J Soc Psychiatry 2010; 57(2): 180-94.
11. Janardhana N, Raghunandan S, Naidu DM, Saraswathi L, Seshan V. Care giving of people with severe mental illness: An Indian experience. Indian J Psychol Med 2015; 37(2): 184-94.
12. Thara R, Padmavathi R, Kumar S, Srinivasan L. Burden Assessment Schedule: Instrument to assess burden on caregivers of chronically mentally ill. Indian J Psychiatry 1998; 40(1): 21-9.
13. Singh M, De Sousa A. Factors affecting depression in caregivers of patients with schizophrenia. J Mental Health Hum Behav 2011; 16(2): 87-94.
14. Derajew H, Tolessa D, Feyissa GT, Addisu F, Soboka M. Prevalence of depression and its associated factors among primary caregivers of patients with severe mental illness in southwest Ethiopia. BMC Psychiatry 2017; https://doi.org/10.1186/s12888-017-1249-7.
15. Garg K, Kumar CN, Chandra PS. Number of psychiatrists in India: Baby steps forward, but a long way to go. Indian J Psychiatry 2019; 61(1): 104-5.
16. Kroenke K, Spitzer RL, Williams JBW. The PHQ-9. Validity of a Brief Depression Severity Measure. J Gen Intern Med 2001; 16(9): 606-13. Doi:10.1046/j.1525-1497.2001.016009606.x
17. Grandon P, Jenaro C, Lemos S. Primary caregivers of schizophrenia outpatients: Burden and predictor variables. Psychiatry Res 2008; 158(3): 335-43.
18. Jenkins JH, Schumacher JG. Family burden of schizophrenia and depressive illness. Br J Psychiatry 1999; 174: 31-8.
19. Padmavathi R, Rajkumar S, Srinivasa TN. Schizophrenic patients who were never treated – A study in an Indian urban community. Psychol Med 1998; 28: 1113-7.
20. Ali RM, Bhatti RS. Social support system and family burden due to chronic schizophrenia in rural and urban background. Indian J Psychiatry 1998; 30: 349-53.
21. Kaya Y, Oz F. Global social functioning of patients with schizophrenia and care burden of caregiving relatives. J Psychiatr Nurs. 2019; 10(1): 28-38.
22. Kuchhal AK, Kuchhal A, Arya V, Pardal PK, Sharma CS, Sharma M. A study of psychological stress and burden on caregivers of schizophrenic patients. Int J Contemp Med Res 2019; 6(8): 111-5. DOI: http://dx.doi.org/10.21276/ijcmr.2019.6.8.2
23. Winefield HR, Harvey ES. Needs of family caregivers in chronic schizophrenia. Schizophr Bull 1994; 20(3): 557-66.
24. Rammohan A, Rao K, Subbakrishna DK. Burden and coping in caregivers of persons with schizophrenia. Indian J Psychiatry 2002; 44(3): 220-227.
25. Roychoudhuri J, Mondal D, Boral A, Bhattacharya A. Family burden among long term psychiatric patients. Indian J Psychiatry 1995; 37: 81-5.
26. Kumar S, Mohanty S. Spousal burden of care in schizophrenia. J Indian Acad Appl Psychol 2007; 33(2): 189-94.
27. Ruchika A, Kumar R, Varghese A. Depression and quality of life in family caregivers of individuals with psychiatric illness. Int J Community Med Public Health 2019; 6(2): 715-20.