

Quality of Sleep among the Primary Care Givers of Patients with Schizophrenia

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Abstract: Schizophrenia is a disabling, chronic psychiatric disorder that affects a person's thinking, language, emotions, social behavior, and ability to perceive reality accurately. Schizophrenia is associated with a significant and long-lasting health, social, and financial burden, not only for patients but also for families. The care givers provide day-to-day care, supervise medication, take patient to hospital and tolerate the behavior of patients. The caregivers' sleep quality is often an under-recognized and undertreated problem that may contribute to negative health consequences. This study was conducted to assess the sleep quality among the primary care givers of patients with schizophrenia. 100 primary care givers were selected using Systematic random sampling method. Pittsburgh Sleep Quality Index was used to assess the sleep quality of primary care givers. Brief Psychiatric Rating Scale was used to assess the severity of symptoms of patients. The findings revealed that most of the primary care givers were above 45 years of age (48%), male (51%), married (82%) and staying with patient for more than 15 years (56%). Quality of sleep was good among the 59% of the primary care givers. There was a significant association between the quality of sleep of primary care givers and their gender ($p=0.016$), their relationship with the patient ($p=0.001$), when they sleep in the same room along with the patient ($p=0.013$), duration of stay with the patient ($p=0.027$), duration of illness of the patients ($p=0.025$) and the severity of illness ($p < 0.000$). Primary care givers experience the illness along with the patient and attend to their needs and forget to care for themselves. It is important to identify the needs of the care givers and educate them on exercise, eating a good diet, sleep hygiene and stress-management techniques that can improve quality of sleep.

Keywords: primary care givers, quality of sleep, schizophrenia.

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I. Introduction

Schizophrenia called arguably the worst disease affecting mankind, is a disabling illness that affects a person's thinking, language, emotions, social behavior, and ability to perceive reality accurately. Schizophrenia is associated with a significant and long-lasting health, social, and financial burden, not only for patients but also for families, other caregivers, and the wider society. Significant amount of time and energy is spent by the caregivers in caring for their loved ones, despite its impact on their personal goals (1). The caregivers play multiple roles such as taking day-to-day care, supervising medications, taking the patient to the hospital and looking after the financial needs (2). Caregivers are referred to as "secondary patients," who need and deserve protection, support and guidance (3). Sleep is one of the beautiful biological components of human activity which is a benevolent boon from God. High-quality sleep has a restorative, protective, and energy-conserving function that lays the groundwork for a productive day ahead (4). Adequate sleep is important for physical and mental well-being and overall quality of life (5). Sleep quality relies heavily on the person's perception and satisfaction of their sleep (6). Sleep deprivation impairs adaptive immunity and increases susceptibility to infectious disease (7). Chronic poor sleep quality increases signs of intrinsic ageing, decreases skin barrier function (8). Decreased duration of sleep increases the risk of death due to cardiovascular diseases (9). Sleep loss for two nights impairs the quality of decision making (10).

The physical effects of caregiving are generally less intensive than the psychological effects. Caregiving results in stress which can manifest as aches and pains in the head and body, difficulty sleeping, increased appetite or decreased appetite, and increased risk for health problems (11). Daily functioning and the care giving quality of the care givers are affected due to their sleep disturbances (12). Caregiving may also be beneficial, in enabling the caregivers to feel good about them, learn new skills, and strengthen their family relationships (13).

As the patients and caregivers experience the illness together, their emotional reactions, distress, and coping styles also might co-affect the sleep in care givers (4). Regardless of their family member's diagnoses, sleep disturbances are commonly reported by caregivers, (14). Often, a caregiver's schedule is focused around the needs and responsibilities of the person who is unwell. This may lead to sleep disturbances during the night, earlier wake times, and later bedtimes (15, 16). While most studies among caregiver focus on their burden and depression, caregivers' sleep quality is often an under-recognized and undertreated problem that may contribute to negative health consequences. There is paucity of literature about the quality of sleep of primary care givers of schizophrenia. It is important to recognize sleep problems in caregivers and to provide appropriate interventions to improve their health outcomes. Therefore this study was done with following objectives,

1. To assess the quality of sleep among the primary care givers of patients with schizophrenia
2. To determine the association between quality of sleep among the primary care givers and selected socio-demographic variables (age, marital status, education, occupation, income, relationship, hours spent in caring, type of family and habitat) of the primary caregivers
3. To determine the association between quality of sleep among the primary care givers and selected clinical variables (age of onset, compliance to treatment, no of psychotic episodes, severity of illness) of patients with schizophrenia

II. Methods

The study was conducted in the Out Patient Department of the Department of Psychiatry, in a multispecialty teaching hospital in South India. Sample size was calculated based on the reports of the pilot study. A cross sectional design was used and 100 primary caregivers were selected as study subjects using Systematic Random Sampling method. Subjects above the age of 18 years, staying with the patient for more than 6 months, able to verbalize and comprehend Tamil or English and gave written consent, were included in the study. Subjects with severe language, hearing, cognitive impairment, psychiatric co-morbidity or intellectual disability were excluded from the study.

II.1: Data collection instruments

II.1.1: The Pittsburgh Sleep Quality Index (PSQI) is a self-report questionnaire that assesses sleep quality over a 1-month time interval designed by (17). It consists of 19 individual items generating seven "component" scores: subjective sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of sleeping medication, and daytime dysfunction. The sum of scores for these seven components yields one global score. A global sum of "5" or greater indicates a "poor" sleeper. The PSQI has internal consistency and a reliability coefficient (Cronbach's alpha) of 0.83 for its seven components. Numerous studies internationally had used this scale that support for high validity and reliability.

II.1.2: The Brief Psychiatric Rating Scale (BPRS) is a widely used instrument for assessing the positive, negative, and affective symptoms of individuals who have psychotic disorders, especially schizophrenia. It consists of 24 symptom constructs and takes 20-30 minutes for the interview and scoring. It also considers the individuals behaviours over the previous 2-3 days and this can be reported by the family. It is scored on an 8 point Likert scale ranging from not present to extremely severe. 0 is scored if the item is not assessed. Scoring is done by summing the scores of 24 items. The score ranges from 0-168 with higher score indicating higher severity of illness. The inter-rater reliability reported in the literature is 0.80. (18).

II.2: Data collection procedure

The primary care givers of patients who attend the outpatient department were recruited for the study. After introducing and explaining the purpose of the study, a written consent was obtained from the subjects. The instruments were administered by the investigator in either of the two languages, English or Tamil according to the relatives' preferences. Each interview was conducted for 30-45 minutes in a separate room.

The study was conducted after getting approval from the College of Nursing Research Committee and the Institutional Review Board. Written informed consent was obtained from the subjects prior to the data collection. The data obtained from the participants were kept confidential.

III. Results and discussion

III.1: Socio-demographic variables of the patients:

Data was analysed using appropriate descriptive (mean, standard deviation) and inferential (chi-square) statistics and was computed using SPSS version 17.

The descriptive analysis of the socio-demographic variables of the patients revealed that the mean age of patients were 33.2±10.0 years. Females (54%) outnumbered males, majority (55%) were married and followed Hindu religion (85%). A study by Brissos et al., (19) revealed that 66% of the patients were males, which is contrary to the findings of the current study. Thirty four percentages of the patients were with

secondary level education, 35% were house wives, 81% with monthly income less than 5000, 53% from nuclear family and 61% from rural area. On the contrary a study by Gaur et al., (20), found that the mean age of patients with schizophrenia was 38.6years, 68% of patients were married and 62% were living in joint family.

III.2: Clinical variables of the patients:

The descriptive analysis of the clinical variables of the patients with schizophrenia revealed that the duration of illness of 36% of patients were 19-24 months, the current episode is the first episode of illness for 56% patients, 62% with good compliance, 88% without any history of previous hospitalization, 54% on antipsychotics and anticholinergic drugs, the severity of illness was low in 51% of patients (mean BPRS score 45 ± 9), 83% had no substance abuse and 93% were without any medical co-morbidities. On the contrary Sajatovic et al., (21) found that 100% of the patients had the mean BPRS score < 45 and in another study done by Mandal ,Prakash & Sagar (22) the mean BPRS score was 32 ± 11 .

III.3: Demographic variables of the primary care givers:

The descriptive analysis of the demographic variables of the primary care givers shows that the mean age of the primary care givers were 44.3 ± 12.6 years, 51% males, 82% married, 85% Hindu, 43% had secondary level education, 100% sleeping in the same house, 86% sleeping in the same room along with the patient, 56% staying with the patient for more than 15 years, 36% giving care for an hour, and 81% without any medical problems, and 39% PCG were spouses of the patients. Similar findings were reported in a study by Mandal , Prakash & Sagar (22) the primary care givers mean age was 44.7 ± 14.6 years. On the contrary a study by Immonen, Jääskeläinen, Korpela, & Miettunen (23) revealed that the mean age of the care givers were 50 years, most of them were females 62% and the mean duration of stay was 17 years.

III.4: Quality of sleep of primary care givers



Fig:1 shows that 59% of the primary care givers had good quality of sleep. Similarly a study done by Immonen, Jääskeläinen, Korpela, & Miettunen (23) also showed that 58% of the care givers had sleep difficulties. On the contrary a study by El-Tantawy, Raya, & Zaki (24) revealed that the 73% of the primary care givers of patients with schizophrenia had restless sleep also another study by Gupta, Isherwood, Jones, & Van Impe (25), found that 42.7 % of caregivers of patients with schizophrenia had more sleep difficulties and 32.4 % had insomnia. The primary care givers of young unmarried patients mentioned that they worry about the future of their patients and that is one of the major reasons for their sleep disturbances.

III.5: Table 1 Association between the socio demographic variables of the primary care givers and their Quality of Sleep N=100

Variable	Quality of sleep				P value
	Good (PSQI <5)		Poor (PSQI >5)		
	N=59	N=41	N=59	N=41	
	n	%	n	%	
Age in years					
<25	4	57.1	3	42.9	0.379
26-35	15	75	5	25	
36-45	15	60	10	40	
>45	25	52.1	23	47.9	
Gender					
Male	36	70.6	15	29.4	0.016*
Female	23	49.6	26	53.1	
Marital status					
Single	4	57.1	3	42.9	
Married	51	62.2	31	37.8	0.349
Widow/widower	4	40	6	60	
Separated	0	0	1	100	
Education					
Illiterate	0	0	1	100	0.407
Primary	15	46.9	17	53.1	
Secondary	27	62.8	16	37.2	
Higher secondary	8	72.7	3	27.3	
Graduate/ Post graduate	7	70	3	30	
Technical/ Diploma	2	66.7	1	33.3	
Occupation					
Unemployed	1	50	1	50	0.095
Housewife	12	42.9	16	57.1	
Skilled	10	83.3	2	16.7	
Unskilled	22	62.9	13	37.1	
Business	9	75	3	25	
Professional	4	66.7	2	33.3	
Retired	1	20	4	80	
Relationship with the patient					
Parent	18	42.9	24	57.1	0.001*
Spouse	33	84.6	6	15.4	
Children	2	33.3	4	66.7	
Sibling	6	60	4	40	
Grand parent	0	0	2	100	
Daughter in law	0	0	1	100	
Patient and PCG Sleeping in the same room					
Yes	55	64	31	36	0.013*
No	4	28.6	10	71.4	
Duration of stay with the patient					
≤5 years	14	51.9	13	48.1	0.027*
6-15 years	15	88.2	2	11.8	
>15 years	30	53.6	26	46.4	
Time spent in providing care					
30 minutes	16	66.7	8	33.3	
One hour	23	62.2	14	37.8	0.180
2 hours	13	65	7	35	
>2hours	7	36.8	12	63.2	

*p<0.05

Table 1 reveals that significant association was found between the quality of sleep of PCG their gender (p=0.016), their relationship with the patient (p=0.001), when they sleep in the same room along with the patient (p=0.013), and duration of stay with the patient (p=0.027). In Indian culture care giving is traditionally entrusted mostly on the female member of the family, which might be a reason that their quality of sleep is affected more. A mother of a young unmarried female patient mentioned, 'I am not able to concentrate in anything, everyone in my place is now aware of my daughters illness and when I think of her future and marriage I am not able to sleep'. This clearly explains the impact of stigma related to mental illness on the primary care givers sleep. While assessing the quality of sleep many of the female primary care givers, openly shared their problems such as financial burden, disappointments, lack of support and fear of patients future. When the care givers sleep in the same room along with the patient the tendency to wake up in the middle of the night to check on the whereabouts of the patients were also reported by the primary care givers.

III.6: Table 2 Association between clinical variables of patients and the quality of sleep of PCG (N=100)

Variables	Quality of sleep				P value
	Good (PSQI <5) N=59		Poor (PSQI >5) N=41		
	N	%	n	%	
1. Duration of illness					
less than one year	27	77.1	8	22.9	0.025*
1 to 1.5 years	14	48.3	15	51.7	
>1.5 years	18	50	18	50	
2. No of episodes of illness					
1	38	67.9	18	32.1	0.165
2	20	48.8	21	51.2	
3	1	50	1	50	
4	0	0	1	100	
3. Medication compliance					
Good	40	64.5	22	35.5	0.152
Poor	19	50	19	50	
4. No of hospitalization					
Nil	54	61.4	34	38.6	0.102
Once	5	55.6	4	44.4	
>Once	0	0	3	100	
5. Severity of symptoms					
<45	39	76.5	12	23.5	0.000*
≥45	20	40.8	29	59.2	

*p<0.05

Table 2 shows that there is a significant association between the sleep of primary care givers and duration of illness (p=0.025), and the severity of illness (p<0.000). When the patients' symptoms are severe, and have risk of harm to self and others the primary care givers tend to stay awake to keep a vigil on the patient. There are not many published researches on this topic, which necessitates the replication of such studies with large number of samples.

IV. Conclusion

The finding of the study is limited to the subjectivity of the subjects. In the assessment of sleep quality other factors that can also affect sleep such as voluntary sleep curtailment, family worries, work place challenge, travel, environmental factors like noise, role demand, watching TV and financial constraints were not considered. Nursing classes should also discuss the effects of care giving in chronic illnesses. Periodic sleep assessment and supportive counselling for the care givers would help the care givers to feel supported. There are few studies in India focusing on the quality of sleep of the care givers of patients with schizophrenia. Research with large samples in this area will help to contribute or refute the findings.

Primary care givers experience the illness along with the patient and attend to their needs and forget to care for themselves. It is important to identify the needs of the care givers and educate them on exercise, eating a good diet sleep hygiene and stress-management techniques that can improve quality of sleep. This not only impacts their own health by causing anxiety and depression in them but also can indirectly lead to worsening of the patient's condition, as the role of the care givers is crucial in the overall prognosis of such patients.

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