

Research report

RELATIONSHIP BETWEEN SLEEP QUALITY AND PSYCHOLOGICAL WELL-BEING AMONG CAREGIVERS OF PATIENTS WITH MENTAL ILLNESS

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ABSTRACT

Background: Caregivers of patients with serious mental illness suffer from poor sleep quality and quality of life due to strong dependency of patients on caregivers. Addressing the caregiver burden and its effect on their physiological and psychological aspect of well-being can improve patient outcomes. **Objectives:** The study aimed to assess the correlation between sleep quality and psychological well-being among caregivers of patients with mental illness. The study also examined the association between the sleep quality of caregivers and selected variables such as age, gender, education, and occupation. **Methods:** A cross-sectional survey was used. Data were collected from 112 caregivers, who attended the outpatient psychiatry clinics of Government Medical College Hospital, Kozhikode, Kerala. Socio-personal data of caregivers as well as socio-personal and clinical data of patients were collected using a semi-structured interview schedule and record review. Sleep quality was assessed using Pittsburgh Sleep Quality Index (PSQI) and psychological well-being was assessed using Ryff's Psychological Wellbeing Scale (RPWBS). Data were subjected to descriptive and inferential analysis. **Results:** Findings revealed that 59 (52.6%) caregivers experienced poor sleep quality (global PSQI score >5). A significant negative correlation was observed between the sleep quality index (PSQI score) and the psychological well-being (RPWBS score) of the caregivers. Findings also showed that the male gender, higher educational level, Above Poverty Line socioeconomic status, absence of lifestyle diseases, and joint/extended family were associated with better sleep quality. **Conclusion:** It is important to understand various psychological and physiological effects of caregiver burden in mental illness. Interventions targeting families where relatives experience mental health problems are important to prevent relapse and promote recovery in the patients. The psychological health of caregivers is affected by insufficient sleep, which can negatively impact patient outcomes. These results suggest close monitoring of the caregivers' mental health and the provision of family-focused interventions.

Key Words: Caregiver, mental illness, sleep quality, psychological wellbeing

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INTRODUCTION

According to the Global Burden of Disease Study, one in seven Indians were affected by mental disorders of varying severity in 2017.¹ In more than 90% of the cases, family members are the primary caregivers of persons with mental illnesses in India.² Caregivers providing care to mentally ill family members are at risk for caregiver burden and declining physical and psychological health.³ Caregiving is emotionally and cognitively demanding, and it affects the caregiver's overall health. Due to responsibilities associated with caregiving, sleep disturbances lead to changes in the individual's mental, physical, and cognitive health.⁴ Inadequate sleep quality impact many physiologic systems and general health.⁵ Poorer subjective sleep quality in caregivers of patients with mental illness has been reported in several studies.⁶ Well-being of the caregiver affects the quality of care received by the patient. Psychological issues of caregivers have an effect on patient outcomes. Patient and caregiver are considered as a single unit when suffering related to mental health problems is discussed.⁷ Sleep deprivation results from environmental, personal, and developmental issues. Unexpected environmental disturbances lead to arousal from sleep, which caregivers of patients with mental illness frequently experience. Similarly, physiological and psychological stressors influence the personal or internal environment.⁸

Caregivers of mentally ill individuals experience a lot of burden; the highest burden is seen in the domains of physical and mental health, spouse-related, and external support.⁹ Psychotic conditions like bipolar affective disorder and schizophrenia are associated with a considerable degree of perceived burden by caregivers.¹⁰ Caregiving role can be stressful and burdensome. Caregiving has features of chronic stress experience. The health effects of caregiving have been studied, and the knowledge has helped in public health policy decisions.¹¹ Though the health effects of

caregiving have been studied earlier, research on sleep quality and psychological well-being is scarce in India. This study examined the relationship between sleep quality and psychological well-being among caregivers of patients with mental illness attending a tertiary care hospital in northern Kerala. The study also investigated the association between sleep quality and the socio-demographic variables of the caregivers.

METHODS

A cross-sectional survey was adopted for the study. The study was conducted in the outpatient psychiatry clinics of Government Medical College Hospital, Kozhikode. The study population constitutes the caregivers of patients with mental illness. Caregivers fulfilling the eligibility criteria were selected consecutively. The sample size was calculated based on a study examining the role of sleep quality in the psychological well-being of a student population, which reported a moderate level of association between the variables.¹² Considering the effect of covariates such as age, gender and education on sleep and psychological well-being, the sample size was set at 112. Caregivers of patients with mental illness who were free from any serious physical or mental illness were included in the study. Mental illness in this study refers to conditions diagnosed under the ICD-10 Classification of Mental and Behaviour Disorders, including schizophrenia and related disorders, mood disorders, substance use disorders, and anxiety spectrum disorders.¹³ Caregivers of patients with the first episode of illness were excluded.

Data collection tools for the study included a semi-structured interview schedule to collect the socio-personal variables of the caregiver and clinical variables of the patient. The socio-personal variables were selected as per their importance in relation to the sleep quality and psychological well-being of the caregiver. It consists of items related to age, gender, marital status, education status, family type,

occupation, socio-economic status, relations with the patient, presence of lifestyle diseases, and patient-related variables such as age, gender, diagnosis, age of onset, duration of illness and frequency of follow-up. The content validity of the tool was established by experts in the field of mental health care.

Pittsburgh Sleep Quality Index (PSQI) is designed to measure the quality of sleep among persons above 18 years of age. The self-rating questionnaire evaluates sleep quality over the past one month. Nine items generate seven component scores: subjective sleep quality, sleep latency, sleep duration, sleep efficiency, sleep disturbance, use of sleep medication, and daytime dysfunction. The sum of these seven component scores yields one global score. Each component score has a value of '0' (no difficulty) to '3' (severe difficulty). The global score can range from '0' to '21' and a score of more than 5 suggests poor sleep quality.¹⁴ Higher scores on PSQI signifies lower sleep quality. Permission was obtained for the use of the scale in this study. PSQI has been found to have good psychometric properties.¹⁴ The tool was translated into Malayalam, and language validity was established using translation and re-translation procedures. The content validity of the translated tool was established. Additionally, subjective experience of sleep interruption due to caregiving was collected from the participants using a single item.

RYFF'S Psychological Well-being Scale (RPWBS) is an 18-item scale with six domains: autonomy, environmental mastery, personal growth, positive relation with others, purpose in life, and self-acceptance. Each domain consists of 3 questions and a maximum of 15 marks with five options to select the degree of agreement and disagreement towards the given statements. Adding the scores of respondents' answers to each question provides a subscale score, and the sum of the six subscale scores gives the total score. A higher score indicates higher psychological

well-being.¹⁵ In addition to the quantified well-being index, an additional question was asked about their psychological distress due to the caregiver role. The scale is in the public domain for academic purposes, and permission was obtained from the author. The scale was translated into Malayalam, and language validity was established through back-to-back translations.

A research protocol was developed to standardize the assessment procedure. A pilot study was conducted to understand the feasibility of the research. The research was approved by Institutional Ethics Committee and administrative permission was obtained from the authorities of the institutions. Written informed consent was obtained from individual participants. Data collection was performed from 01/03/21 to 12/03/21 at outpatient psychiatry clinics of a tertiary care hospital in Northern Kerala. A total of 112 caregivers of patients with mental illness satisfying the inclusion criteria were selected. Collected data were analysed using the Statistical Package of Social Sciences (SPSS) package for Windows, version 18.0. Pearson correlation coefficient was estimated and group difference tests were applied to examine the association between the variables.

RESULTS

The demographic characteristics of caregivers are given in Table 1. Analysis of socio-personal variables shows that 50.9% of the caregivers were in the 21-40 years age group, 65.2% were females, 61.6 % were married, 57.1% were from the nuclear family, 41.1% were unemployed, 37.5% were with a degree/higher education and 59.8% belonged to Below Poverty Line (BPL) socio-economic category (Table 1). The mean age of the caregivers was 41.67 (Standard Deviation [SD] - 10.92) years and the mean years of education was 11.97 (SD - 3.17). Among the caregivers, 11.6% had a history of mental illness, 8% had a substance use history and 30.4% had lifestyle diseases. Parents (32.1%), siblings (23.2%), children

Table1: Sample characteristics of caregivers

Characteristics & Categories	Frequency (%) (N=112)
<i>Age in years</i>	
21-30	18 (16.1)
31-40	39 (34.8)
41-50	35 (31.3)
>50	20 (17.9)
<i>Gender</i>	
Female	73 (65.2)
Male	39 (34.8)
<i>Marital status</i>	
Married	69 (61.6)
Unmarried	20 (17.9)
Separated/ widowed	23 (20.5)
<i>Type of family</i>	
Nuclear	64 (57.1)
Joint/ extended	48 (42.9)
<i>Socioeconomic status</i>	
Above poverty line/APL	45 (40.2)
Below poverty line/BPL	67 (59.8)
<i>Religion</i>	
Hindu	43 (38.4)
Muslim	56 (50.0)
Christian	13 (11.6)
<i>Education</i>	
Primary	11 (9.8)
Secondary	33 (29.5)
Higher Secondary	26 (23.2)
Degree/higher	42 (37.5)
<i>Occupation</i>	
Coolie	19 (17.0)
Business	9 (8.0)
Agriculture	7 (6.3)
Government/ private/ regular income jobs	31 (27.7)
Unemployed	46 (41.1)

(21.4%) and spouses (17.9%) constituted most of the caregivers and another 5.4% were other relatives or friends.

Analysis of patients' characteristics shows 59.8% were females and 57.5% were in the 21-40 years age group. The mean age of the patients was 40.24 (SD - 15.22) years (see Table 2). It was found that 34.8% had a period of 1-5 years, 48.2% had 6-10 years and 17%

had more than ten years of duration of illness. The average duration of illness was 7.24 (SD - 5.8) years. Nearly 24% of patients were diagnosed with mental illness before the age of 20 years. It was found that 76.1% were taking regular treatment. Schizophrenia and psychotic disorders were the diagnoses as per ICD-10 in 42 (37.5%) patients, 24 (21.4%) had bipolar disorders and 20 (18%) had depressive disorders. Anxiety and stress-related disorders were seen in 21 (18.8%) participants and substance use disorder was diagnosed in 5 (4.5%) patients. Nearly half (44.2%) of patients presented with moderate symptoms and 24.8% with severe symptoms.

Sleep Quality and Psychological Well-Being

Findings show that more than half (52.7%) of the participants experienced poor sleep quality. The mean score of Global PSQI was 6.83 (SD - 4.62), and a higher score signifies poor sleep quality. Nearly half (38.4%) of the caregivers in this study verbalized the presence of sleep interruption. More than half (64.7%) of the caregivers verbalized the presence of psychological distress due to the caregiver role. The mean score of RPWBS was 57.94 (SD - 8.97); a higher score signifies better psychological well-being.

There was a significant negative correlation ($r = -0.55$; $p = 0.001$) between the global PSQI score and RPWBS score in caregivers of patients with mental illness. A higher score on PSQI indicates lower sleep quality. The six domains of wellbeing-scale, RPWBS, such as

Table 2: Patient characteristics

Characteristics	Frequency (%) (N=112)
<i>Age in years</i>	
21-30	34 (30.1)
31-40	31 (27.4)
41-50	18 (15.9)
51-60	19 (17.7)
>60	10 (8.8)
<i>Gender</i>	
Female	67 (59.8)
Male	45 (40.2)

autonomy ($r = -0.48$; $p = 0.001$), environmental mastery ($r = -0.29$; $p = 0.02$), personal growth ($r = -0.47$; $p = 0.001$), positive relationship ($r = -0.47$; $p = 0.001$), purpose in life ($r = 0.2$; $p = 0.03$) and self-acceptance ($r = 0.48$; $p = 0.001$) were also negatively correlated with global PSQI score.

Relationship Between Sleep Quality and Selected Variables

An increasing score on PSQI was positively correlated with the caregiver's age ($r = 0.33$; $p = 0.001$), indicating a correlation between increasing age and poor sleep quality. Gender difference shows female caregivers had significantly poor sleep quality ($t = 2.94$, $df = 110$; $p = 0.004$). Divorced/widowed and unmarried caregivers reported significantly worse sleep quality than married participants. Participants with primary-level and secondary-level education experienced significantly poor sleep quality compared to participants with degree/professional education ($F = 8.87$, $df = 2, 109$; $p < 0.001$). Similarly, participants from BPL socioeconomic class ($t = 2.9$, $df = 110$; $p = 0.005$) and nuclear family ($t = 0.21$, $df = 110$; $p = 0.034$) had comparatively poor sleep quality. Participants with lifestyle diseases had poorer sleep quality (see Table 3).

The gender of the patient was not significant regarding the caregiver's sleep quality (female patients' caregivers' PSQI score = 6.87 [SD = 4.65]; male patients' caregivers' PSQI score = 6.78 [SD = 4.64]) ($t = 0.098$, $df = 110$; $p = 0.92$). Caregivers' sleep quality was also not significantly related to the age of the patient ($r = 0.07$; $p = 0.47$) and the duration of the patient's mental illness ($r = 0.077$; $p = 0.42$). Diagnosis of the patient was also not associated with the sleep quality of the caregivers. Caregivers of patients who had regular follow-up had a significantly better quality of sleep ($n = 86$; PSQI score = 5.6 [SD = 3.85]) in comparison to the group with irregular follow-up ($n = 26$; PSQI score = 10.96 [SD = 4.62]) ($t =$

5.94, $df = 110$, $p = 0.001$).

DISCUSSION

Improved sleep quality also improves mental health.⁶ Relatives of patients with major psychiatric disorders feel burdened; that burden is experienced in the form of disruption of family function, well-being, health problems, and various issues with one's personal life.¹⁶ Poor sleep quality in caregivers of mental illness is a significant health problem that should be recognized and addressed. Sleep complaints have been under-recognized and undertreated in caregivers of mentally ill persons.¹⁷ Role of the family becomes more important in the care of the mentally ill in India as rehabilitation services are scarce and social security systems are inadequate.¹⁶ High levels of burden, stress, and depression, as well as increased risk for mortality, have been reported in caregivers of people with mental illness.¹⁸ Caregiving-related stress and its impact on health have been studied in different contexts in the past.¹⁹

We found a significant relationship between sleep quality and caregivers' well-being. All the domains of the RPWB scale, such as autonomy, personal growth, environmental mastery, positive relationship, purpose in life, and self-acceptance, were related to sleep quality. Autonomy is an important component of well-being often affected in caregivers of people with mental illness. We found autonomy domain was related to sleep quality. Better information to the patient and caregiver and encouraging caregivers to participate in decision-making and collaborative treatment planning would improve the feeling of autonomy in caregivers, which would eventually benefit patient outcomes.²⁰ Qualitative studies are required to understand the caregiver perspectives of autonomy and the hindrances they are facing.²¹

Similarly, we found personal growth domain of the well-being scale was related to sleep

Table 3: Comparison of quality of sleep among caregivers based on selected variables

Characteristics	Group	Mean (SD)	t-test/ ANOVA	p-value
Gender	Female(n=73)	7.74 (4.63)	t = 2.94 (df = 110)	.004**
	Male (n=39)	5.13 (4.18)		
Marital status	Married (n=69)	3.90 (3.32)	F = 5.78 (df = 2, 109)	.001**
	Unmarried (n=20)	6.83 (4.6)		
	Divorced/widowed (n=23)	9.39 (4.28)		
Education	Primary (n=11)	11.00 (4.58)	F = 8.87 (df = 3, 108)	<.001**
	Secondary (n=33)	8.42 (4.24)		
	Higher Secondary (n=26)	6.50 (4.42)		
	Degree /higher (n=42)	3.92 (3.92)		
Socio-economic status	APL (n=45)	5.33 (4.45)	t = 2.9 (df = 110)	.005**
	BPL (n=67)	7.84 (4.51)		
Lifestyle disease	Present (n=34)	9.82 (4.33)	t = 4.97 (df = 110)	.001**
	Absent (n=78)	5.53 (4.14)		
Type of family	Nuclear (n=64)	6.03 (4.49)	t = 0.21 (df = 110)	.034*
	Joint /extended (n= 48)	7.90 (4.64)		

df – degrees of freedom, * – significant at 0.05 level, ** – significant at 0.01 level

quality. In general, Ryff's concept of personal growth refers to the growth resulting from caregivers' situation rather than from life experience.²² The relationship between caregiving and personal growth in caregivers of patients with mental health problems becomes positive when the experience is less burdensome.²³ Purpose in life, meaning to their life, is also a component of well-being related to caregiving when the negative effects may not occur.¹¹ Self-acceptance and self-esteem are heightened in caregivers as a positive consequence due to caregiving. But excessive caregiver burden will have a negative consequence on self-acceptance and self-esteem. It is found that as sleep quality deteriorates, self-acceptance decreases.²⁴

The role of sleep quality in psychological well-being as well as the health consequences of sleep disruption in various populations, have been studied earlier.^{12,25} But not much research has focused on the quality of sleep and well-being of caregivers of people with mental illness. We found that the age of the caregiver was negatively associated with sleep quality. As age increases, sleep quality worsens. It has been reported in earlier research that age was negatively related to

burden score; possibly, the older caregivers accepted the role of care.³ Lifespan changes in sleep quality are multifaceted and different reasons exist for changes in sleep quality.²⁶ The result of this study should be viewed in the context of multiple factors of aging and caregiving demands on one's health when age advances.

The low level of education of the caregiver is an independent predictor of the high burden of care.²⁷ We found that caregivers with primary-level education had significantly poorer quality of sleep. Low educational status leads to social and economic disadvantage and an inability to meet the demands of caregiving. Lower educational attainment may negatively affect caregiver's knowledge and understanding of the illness, which in turn increases stress and affect their physiological functions, including sleep quality.²⁷

We found that sleep quality was poorer among female caregivers than male caregivers. In this study, more than half of the caregivers (65.2%) and more than half of the patients (59.8%) were females. Generally, caregiving is a common issue that impacts women's sleep, as 66% of informal caregivers are women.¹⁷ Research on gender differences in sleep

disorders shows that women have better sleep quality than men in the general population, though subjective sleep complaints are more common in women.²⁸ Studies have examined gender differences among family caregivers of people with mental illnesses and concluded that women spend more time providing care and carrying out personal-care tasks more often than men. Women experience greater mental and physical strain, greater caregiver burden, and higher levels of psychological distress while providing care.²⁹

Socioeconomic status was a significant factor in deciding sleep quality. We found that caregivers from low socioeconomic status (BPL) reported significantly poorer sleep quality. Similar studies from India have also reported a higher proportion of caregiver burden in low socioeconomic status group.⁹ The association between lifestyle diseases and sleep quality has been well-studied.³⁰ We found that the presence of lifestyle diseases in caregivers of people with mental illness was associated with poorer quality of sleep.

This study was subject to several limitations. Numerous factors contribute to poor sleep quality and psychological well-being in caregivers of people with mental illness. We studied the important factors that contribute to subjective sleep quality and well-being. Despite the limitations, findings recommend a greater focus on the physiological and psychological needs of caregivers of patients with mental illness.

Conclusion

Caregivers of people with mental illness experience enormous burden while providing care for their relatives with mental illness. Based on our findings, we recommend strengthening and promoting existing support systems to ease the mental stress of family caregivers of patients with mental illness.

Conflicts of Interest

The authors declare no conflict of interest.

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