

Sleep Quality: A Mediation Analysis in the Dynamic between Stress and Quality of Life among Caregivers of Children with Disabilities

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The current study aims to examine sleep quality as a mediating factor in the relationship between stress and quality of life of caregivers of children with disabilities. 219 participants of this study were the caregivers of children with disabilities. Data was collected from the participants using The Kingston Caregiver Stress Scale, Pittsburgh Sleep Quality Index and the Flanagan's Quality-of-Life Scale. Structural Equation Modelling revealed a fit model and also pointed out that sleep quality partially mediated the otherwise negative relationship between stress and quality of life of caregivers of disabled children.

Keywords: caregivers, sleep quality, stress, quality of life

Disability among children is one of the burning problems in India and around the world. Children with disabilities are one of the most marginalized and expelled community of the population. These children are with long-term functional limitations which prevent them from full and effective participation in the society. They are often facing discrimination in forms of neglect, abuse, negative attitudes and deprived from easy access to healthcare, education and even survival. According to UNICEF global report 2021, nearly 240 million children experience developmental disabilities including intellectual disability, autism, or a speech disorder. As per the 2011 census, there are 2.68 crore people (56% males and 44% females) with disabilities which consists of 2.21% of the total population region in the country and the majority resides in rural areas (69%).

Caregivers are those providing services to an individual who is unable to take care of him/herself. The caregivers may be broadly classified as formal or informal. Formal ones are hired by the institutions or agencies on regular or intermittent basis and the family

caregivers are the informal types. The parents of the child are the typical caregivers in majority of the cases. The role of the caregiver for special children includes major roles of basic essential needs such as feeding, bathing, giving medications and minor roles of stimulation and optimum development. These caregivers are the vital stakeholders in securing the overall well-being of the special children. They are experiencing many stressors in their day-to-day lives. The active and intense duties of caregivers towards the disabled children are overwhelming finally makes them exhausted. However, the inability to cope with stressors negatively affects physical, mental and overall functioning of the caregivers. Caregivers experience symptoms of guilt, anxiety, depression, anger, insomnia, generalised muscle pain and headaches. As they are central to the child's care in providing unpaid support, different adaptations can have varying effects on the health and well-being of caregivers thus subsequently affects the caregiver role negatively. Caregiver role stress is a global challenge even in developed nations. Most of the focus and service

delivery are concentrating only on the special children thus neglecting the caregiver. The cultural expectations on caring for these children results in caregiver stress. The special children entirely depend on the caregivers for their daily-living results in negative impact of the caregivers ranging from stress to developing physical and mental health problems.

Stress is a bodily response to frustrating moments or events and the chronic stress can be detrimental to an individual's health (Benavides, 2019). The Transactional model of Stress and Coping (Lazarus and Folkman, 1984) states that stress is an individual's ability to handle and adapt to challenges and problems stems from transactions that takes place between them and their environment. Stress in long term results in physical impairment of an individual leaves them emotionally drained. Most of the caregivers offer a massive array of nurturing and services to the children with disabilities. In the end, the caregivers are the hidden victims and are at increased risk of adverse physical and psychological conditions related to the chronic stress. Henceforth, the caregivers are tired, exhausted, stressed and isolated from the social life as they are constantly meeting the daily and long-term needs of the children. Furthermore, the psychological distress can be exacerbated by social stigma, isolation and unfair policies (Carnevale et al., 2008). In comparison with others, mothers facing a disproportionate share of challenges and responsibilities in raising their disabled children and chronic absence of fathers leads to more care giving burden and stress of the mothers (Thomas et al; 2020). Conversely, as most of the time is devoted for the children, there is a low prioritization for the caregiver's health, well-being, personal self care and interests. Factors like poorer functioning of the child, family dysfunctions, restricted social participations, inadequate social support,

financial insecurity and inaccessible health services limits the autonomy of the caregivers eventually leads to the chronic stress and burnouts (Thurston et al., 2011). On the other hand, family and social support associated with lower stress of the caregivers (Rosensweig et al., 2002). Empirical evidences states that the caregivers of disabled children prone to higher levels of psychological distress in comparison with the caregivers of normal children (Blacher et al., 2009). A negative insight and simultaneously gratifying the challenges of their disabled children leads to stress and deteriorating quality of life among caregivers (Chakraborty et al; 2019).

Adequate sleep is crucial for individual's well-being and is firmly connected with their overall life quality. As sleep encompasses possibly one third of the human life, sleep is vital for decision-making and can influence mood, judgement, memory and one's ability to learn new things (Mattos, 2024). Healthy sleep schedule involves adequate duration and quality, consistent timing and constancy and the lack of sleep disruptions (Watson et al; 2015). Poor sleep has adverse effects on physiological and psychological outcomes with both short and long term effects. These effects are widely varied across multiple body systems thus negatively impact on overall functioning of the body. The intricacy of the care giving demands affects the sleep quality of the caregivers in general (Leggett et al; 2018, Liang et al; 2020). In longer durations, poor sleep is a risk marker for the prevalence of sleep-disorders. If the informal care giving is more demanding and stress-provoking, there are greater sleep disturbances in an individual.

Quality of life is as an individual's subjective evaluation of their reality based on their goals as seen through the framework of their cultural context and values. It is a multifaceted concept describes an

individual's holistic degree of happiness and satisfaction in all aspects of life. As the caregivers of children with disabilities adapt on the several aspects in their lives to meet their child's need consequently affecting their quality of life (Rao et al; 2021). In Indian tradition, with the concept of interdependence and caring for the near and dear ones, the caregivers bear the whole burden thereby affecting their overall functioning. Taking care of both disabled child and family members on a daily basis lead to potential decline in quality of life (Sulaimani et al; 2023). The long-term reliance of the child on the caregivers causes emotional stress, fatigue and lack of sleep which affects their overall quality of life (Isa et al; 2021). Quality of life among caregivers affected by various factors such as severity of the disability in child, financial assistance, caregiver's age and lack of social support services in both direct and subtle ways. Besides the physical complaints, the psychological stressors and maladaptive coping affects the quality of life among caregivers which prevents them from dynamic participation in the society. Only limited studies have investigated the impact of sleep in caregiver's stress and overall quality of life. Hence, the present study concerns about the sleep quality as a factor of importance in the stress and quality of life among caregivers of children with disabilities.

Objectives

- To explore the levels of stress, sleep quality and quality of life among caregivers of children with disabilities
- To investigate the relationship between stress, sleep quality and quality of life of caregivers of children with disabilities
- To investigate if sleep quality has mediating effect on the relationship between stress and quality of life of caregivers of children with disabilities

Hypotheses

- There will be a significant relationship between stress, sleep quality and quality of life of caregivers of children with disabilities
- There will be a significant mediating effect of sleep quality on the relationship between stress and quality of life of caregivers of children with disabilities

Method

Sample

The selection of the participants was done through purposive sampling method. A total of 219 participants with age range from 27 to 45 years. Participants who met the criteria for inclusion and exclusion were recruited.

Tools

The Kingston Caregiver Stress Scale (KCSS) by Hopkins and Kilik in 2005 is used to monitor stress among caregivers. The 10 items in three categories of family, care giving and financial issues which rated on a Likert scale from 1 to 5. Higher scores indicating higher caregiver stress. This scale possesses good internal consistency (Cronbach's alpha of 0.82).

Pittsburgh Sleep Quality Index (PSQI) constructed by Buysse et al., 1988 measures the quality of sleep over a one-month. It consists of 19 self-reported items. This scale has an internal reliability of 0.83 and good test-retest reliability and acceptable construct validity.

The Quality-of-Life Scale (QOLS) developed by Flanagan in 1978. This consists of 16 item counts rated on a seven-point Likert scale. The total scores ranges from 16 to 113. Higher scores indicate higher quality of life. This scale has a Cronbach's alpha of 0.82 internally consistent with convergent validity.

Ethical Statement

The authors hereby declare compliance with Ethical Statement. Ethical approval has been taken from the Human Ethical Committee of the University of affiliation that has granted approval for the study.

Procedure

A cross-sectional study was carried out in regional rehabilitation centres and special education schools. A total of 277 questionnaires were given to the participants and 219 are with complete responses filling both the demographic details and questionnaires measuring stress, sleep quality and quality of life were available for analysis. Participants were guaranteed with confidentiality. Among the 219 participants, majority of the caregivers were biological mothers and grandparents. The types of diagnosis in children were mostly Autism, ADHD, Cerebral palsy, Intellectual disabilities and Specific learning disabilities which were reported by their parents as well as the disability identity cards issued by the Government of India.

Results

Table I. Correlation between Stress, Sleep Quality and Quality of Life

N= 219

Variables	Stress	Sleep Quality	Quality of Life
Stress	1		
Sleep Quality	-0.51**	1	
Quality of Life	-0.53**	0.29**	1

**Significant at the 0.01 level

Table 1 indicates a positive correlation of sleep quality with quality of life while there is a negative correlation between stress with sleep quality and quality of life. It can be interpreted that as stress increases, the sleep quality levels and the quality-of-life levels decrease vice versa. Hence, the

Hypothesis 1, “There will be a significant relationship between stress, sleep quality and quality of life of caregivers of children with disabilities” is accepted.

Next, an attempt was made at the mediation analysis. The “causal steps approach” developed by Baron and Kenny (1986) was used to examine the mediation effect of the independent variables. The bootstrap method proposed by Preacher and Hayes (2008) was used to assess the mediation effect’s statistical significance.

Following three guidelines proposed by Baron and Kenny (1986), the mediating roles of sleep quality (SQ) in the link between stress (S) and quality of life (Q) levels were investigated. The first requirement was that there has to be a strong correlation between stress and quality of life, both of which are independent variables. Second, there must be a substantial relationship between the two variables examined here, namely quality of life, which is the outcome variable and sleep quality the mediator variable. The third condition is that there ought to be a reduction in the strength of the correlation between the two variables when the mediator variable is under control. A reduction in the strength of this relationship is recognised as an indication of partial mediation, and the absence of the relationship, that is no correlation as a sign of complete mediation. Three regressions are used to test the mediation:

- Independent variable predicting the dependent variable
 - Independent variable predicting the mediator
 - Mediator and Independent variable together predicts the dependent variable
- The impact of the mediation of sleep quality on the interrelationship between stress and quality of life scores was investigated in the model that was

developed to determine whether the required conditions were met. Three different regression equations were generated, which are shown in Figure 1.

The three regressions are also depicted in Table II.

The mediation regressions are presented in the Table III.

Table II. Regression values for the three regression equations

S.No	Variables	R ²	F	Significance	Effect	Symbol
1	Stress - Quality of Life	0.28	81.77**	0.000	Direct	A
2	Stress – Sleep Quality	0.26	73.64**	0.000	Direct	B
3	Stress – Sleep Quality – Quality of Life	0.29	40.89**	0.000	Indirect	C

**= Significant at 0.01 level

Table III. Regression coefficients for the mediation model with sleep quality as mediator

S.No	Variables	Beta	T	Significance	Effect	Symbol
1	Stress - Quality of Life	-0.53	15.40**	0.000	Direct	A
2	Stress – Sleep Quality	-0.51	8.58**	0.000	Direct	B
3	Stress – Sleep Quality – Quality of Life	0.03	0.49 ^{NS}	0.625	Indirect	C

NS = Not Significant

The above table III indicates the direct and indirect effects through regressions. The symbols denoted are represented in the figure 1 to clarify the mediation relationship. It can be seen that 'c' denotes the third regression equation for mediation analysis. It can be observed that the Beta values of "c" (0.03) is lesser than the direct relationship of 'a' (-0.53), which indicates a partial mediation by sleep quality in the relationship between stress and quality of life. Rule of thumb says that when the regression equation includes the independent variable and mediator predicting the dependent variable is lesser than the equation when the independent variable predicts the dependent variable, there is partial mediation; and when the mediator relationship is absent, then it indicates full mediation (Baron and Kenny, 1986). Here, sleep quality hence mediates the relationship between stress and quality of life. It can be interpreted that care givers who have better sleep quality levels have a better quality of life despite having high levels of stress.

Hence the hypothesis 2, "There will be a significant mediating effect of sleep quality on the relationship between stress and quality of life of caregivers of children with disabilities" is accepted.

Discussion

The current study shows that the sleep quality successfully mediates the relationship between stress and quality of life among caregivers. When the caregivers are stressed, their sleep quality suffers which in turn reduces quality of life. Enhancing sleep quality can act as a buffer against the detrimental impact of the chronic stress. This depicts that when the caregivers have adequate sleep quality, they can manage the issues associated with stress and cope better with quality of life as well. There is also the scenario that having sleep quality would nullify the effects of stress on quality of life. Though there is a lack of a similar study of the mediating influence of sleep quality on this particular relationship between stress and quality of life, there are similar studies analysing the mediating effects of sleep quality as a positive construct. A study by

Feeley (2012) suggests that improving sleep quality in maternal caregivers may have an effect on the quality of life. Good sleep quality can alleviate the negative impacts of stress on quality of life. Another recent study by Carpi and Vestri (2023) explored the possible mediating role of sleep between health-related quality of life and negative emotional states among the medical students of Italy. Sleep quality has the relationship between stress, anxiety, depression and health related quality of life as per the mediation analysis. Hence, sleep quality has a pivotal role in maintaining a good quality of life.

Limitations

The present study has a limited sample and was conducted in a geographical area of one state in India. Further studies can be carried out with a larger sample and include participants from other geographical areas as well.

Recommendations

This study has a great impact in bettering the quality of life of care givers. It has been seen that caregivers are burdened often with duties and responsibilities. If there are steps taken to ensure better rest and recovery, that is better sleep quality, they can maintain a better quality of life despite facing the inevitable stress in their lives. In addition, interventions addressing both sleep disturbances and stress simultaneously can provide better quality of life among caregivers.

Conclusions

There is a significant relationship between stress, sleep quality and quality of life. Sleep quality partially mediates the relationship between stress and quality of life

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