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Evaluation of Sleep Quality and Participation Among Parents of Children with Developmental Disability

Aishwarya Kumari[1], **Janardan Patra**[2]

[1]BOT Intern, College of Occupational Therapy, NIEPMD, Chennai, India
[2]Lecturer & HOD, Department of Occupational Therapy, Composite Regional Centre-Davanagere, NIEPID, Davanagere, India

Corresponding Author: Janardan Patra

Abstract: ***Background**: Concerns about Sleep quality and Participation among parents of disability is growing on a global scale. The stress of caregiving, along with the psychological and physical expenses of managing sleep problems, can negatively impact the parents' personal health and well-being. Parents who don't get enough sleep may find it difficult to perform everyday duties and to participate socially and emotionally. **Aim**: The study aims to explore the correlation between sleep quality and participation among parents of children with developmental disabilities. **Methods**: A cross-sectional study was adopted to assess sleep quality and participation among parents of children with developmental disability. Participants were selected by using convenient sampling technique with the sample size of 61. The purpose of the study was explained to the participant and written consent was received. Sleep Quality was assessed by Pittsburgh Sleep Quality Index and participation is assessed by participation scale and demographic data was also collected. **Results**: The statistical analysis revealed a positive correlation (r=0.346, p=0.006, p<0.05) between sleep quality and participation among parents of children with developmental disability. This study also showed that there was a difference (p < 0.05) in the participation restriction as well as global PSQI score; between males and females. **Conclusion**: The result suggests that there is significant correlation between sleep quality and participation among parents of children with developmental disabilities.*

Keywords: Sleep quality, Participation, Parents, Developmental disability

1.Introduction

Developmental Disability

Developmental impairments are a group of disorders that result from deficiencies in behavior, language, learning, or physical ability. These conditions often begin in childhood, persist throughout an individual's lifespan, and may interfere with day-to-day functioning. While the majority of developmental issues begin prior to birth, some may arise during delivery due to stress, infection, or other factors. (Centre for Disease Control and Prevention, 2013).

The definition of developmental disability in public law 95-602(1978) is not restricted to Mental Retardation and is based on functional criteria. The term "developmental disability" refers to a severe, long-term handicap that is caused by a mental or physical impairment, appears before the age of 22, is likely to persist, requires lifelong care, and results in functional restrictions in three or more key living activities. (1)

The Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM-5; American Psychiatric Association [APA], 2013) further classifies Developmental Disabilities into intellectual disability, communication disorders, autism spectrum disorder (ASD), Attention-Deficit/ Hyperactivity Disorder, specific learning disorder, and motor disorders. There may be an overlap of cognitive, intellectual, and/or learning disabilities as well as motor, sensory, social and communication problems. (2)

Although most developmental problems start before birth, some may occur after delivery as a result of trauma, infection, or other circumstances. People of different races, ethnicities, and socioeconomic backgrounds can have developmental problems. One in six, or roughly 17%, of children in the United States between the ages of three and seventeen have one or more developmental problems, according to recent estimates. India has around 11.5 million cases of developmental impairments in 2016, according to modelled estimates based on the Global Burden of Disease 2016 data (9379•5 to 11 195•6 cases per 100,000 people). (3)

A chronic illness can have a wide range of repercussions on the family, including behavioral, physical, social, personal, and economical. Furthermore, the particulars of chronic pediatric illness play a significant role in determining how it affects the family. The burden of caregiving is more strongly associated with social rejection and stigma than with the actual caregiving and adjustment issues related to the child's illness. (4)

Sleep Quality

The satisfaction of the sleep experience, combining elements of sleep initiation, maintenance, quantity, and wakefulness, is known as sleep quality. (Encyclopedia of behavioral medicine, Marc D Gellman, J. Rick Turner).

It is a complicated physiological process that occurs naturally in every person and typically lasts for almost a third of their life. During sleep, the central nervous system, musculoskeletal system, respiratory system, and circulatory system are all repaired. Additionally, sleep is important for memory consolidation, learning, physical development, mood control, and overall quality of life. Long-term lack of sleep impairs immune system function and raises the risk of diabetes, metabolic disorders, obesity, hypertension, and cardiovascular disease. (5)

Getting adequate sleep has several advantages, including promoting meaningful relationships, feeling rejuvenated, and maintaining regular reflexes. Fatigue, irritation, dysfunction during the day, delayed reactions, and increased consumption of coffee and alcohol are just a few of the detrimental effects of poor sleep quality. The terms "subjective perceived deep sleep," "satisfaction with sleep," "feeling of being well-rested," "actual sleep hours," and "interruptions of sleep during the night" were frequently used to describe the quality of sleep. (6)

Reduced cognitive and physical function, as well as alterations in the immunological, endocrine, metabolic, and inflammatory systems, have all been connected to sleep deprivation. These negative effects have significant effects for parents who are caring for their child overnight and who are coping with both acute and chronic sleep loss and disturbance. Reduced cognitive and physical function, as well as alterations in the immunological, endocrine, metabolic, and inflammatory systems, have all been connected to sleep deprivation. These negative effects have significant effects for parents who are caring for their child overnight and who are coping with both acute and chronic sleep loss and disturbance. (7)

Participation

Participation, according to the ICF model, is defined as involvement in life situations and it is considered as the ultimate health outcome (WHO, 2001). Participation in everyday activities is a product of the interaction of personal and environmental factors. (8)

Participation refers to an individual's involvement in various life situations, which encompass their engagement in broader aspects of daily life and community activities. These areas include social, economic, civic, interpersonal, domestic, and educational domains, all of which are relevant to every person, regardless of their health, age, gender, or background. Difficulties in taking part in any of these life situations are known as "participation restrictions."(9)

Social participation is the nature and extent of a person’s involvement in life situations and events that typically entail being or doing together with others in a social context who seek and utilize social supports within the family or community are optimizing their physical and psychological health t (Law, 2002; World Health Organization, 2001).

Aims and Objective

Aim of the Study:

- To assess sleep quality and participation of parents of children with developmental disabilities.

Objectives:

- To evaluate Quality of sleep and its severity in parents of children with developmental disabilities.
- To evaluate the participation among parents of children with developmental disabilities
- To find the correlation between sleep quality and participation among parents of children with developmental disabilities.

Hypothesis

Alternate Hypothesis:

- There is a significant correlation between sleep quality and participation among parents of children with developmental disabilities.

Null Hypothesis:

- There is no significant correlation between sleep quality and participation among parents of children with developmental disability.

2.Review of Literature

1. **(Brummett, Beverely H)** did on Study “Associations Among Perceptions of Social Support, Negative Affect, and Quality of Sleep in Caregivers and Non caregivers”**.** Study on the associations among comprehensions of social support, negative affect, and quality of sleep- in caregivers andnon-caregivers involved 233 actors. The study set up those caregivers reported poorer sleep quality and advanced negative affect compared caregivers, with perceived social support playing a significant part in moderating these issues. Multidimensional Scale of Perceived Social Support (MSPSS) used to pierce social support. Negative goods were assessed using standardized tone- report measures, the Profile of Mood States (POMS) or the Positive and Negative Affect Schedule (PANAS). Sleep quality was measured through tone- report tools Pittsburgh Sleep Quality Index (PSQI), which assesses colorful aspects of sleep, including duration and disturbances The results suggested that perfecting social support could help palliate the negative emotional impacts and sleep disturbances faced by caregivers. The study concluded that targeted interventions enhancing social support may ameliorate caregiver well- being. (11)

2. **Arora NK, 2018)** conducted a study on “Neurodevelopmental disorders (NDDs) in children aged 2–9 years: Population-based burden estimates across five regions in India”. The study on Neurodevelopmental Disorders (NDDs) in children aged 2–9 years across five regions in India highlights the significant burden of these disorders on public health. Literature suggests that NDDs, including autism, intellectual disabilities, and learning disabilities, are prevalent but often underdiagnosed in lower source settings. The study found that about one in eight children aged 2 to 9 had at least one of the nine NDDs, with the actual burden potentially higher due to study limitations. (12)

3. **(Tatyana Mollayeva,2016)** conducted study on “The Pittsburgh sleep quality index as a screening tool for sleep dysfunction in clinical and non-clinical samples: A systematic review and meta-analysis"**.** The PSQI is extensively used to assess sleep quality and disturbances, and former studies have demonstrated its trustability and validity in colorful settings. Literature suggests that the PSQI is an effective tool for relating individualities with sleep diseases, similar as wakefulness, sleep apnea, and other sleep- related issues. still, its performance may vary depending on the specific population, with some studies showing lower perceptivity innon-clinical groups. The review also highlights the significance of using the PSQI in confluence with other individual tools to enhance its delicacy. It discusses the tool's strengths, similar as its ease of use and capability to capture private sleep quality, while noting the limitations related to tone- reporting impulses. Overall, the review concludes that the PSQI is a useful webbing instrument for relating sleep dysfunction but suggests that its operation should be acclimatized to the specific characteristics of the population being studied. (13)

4. **(Helen Bourke-Taylor,2013)** conducted study on “Relationships between sleep disruptions, health and care responsibilities among mothers of school-aged children with disabilities”**.** Sleep problems are common among children with disabilities, and mothers often provide the primary night time care. A study with 152 mothers of schoolaged children with developmental disabilities (including autism and cerebral palsy) found that nearly half of the mothers were awakened more than four nights per week. Three distinct sleep patterns were identified: no sleep interruption, mild sleep interruption (once per night, 4 nights per week), and more frequent sleep interruption. Mothers experiencing the highest levels of sleep disruption reported poorer health across several dimensions. Additionally, mothers with greater nighttime caregiving responsibilities were less likely to engage in health-promoting activities during the day, such as physical activity or social interactions. (14)

5. **(Chidimma J.,2018)** conducted study on “Burden of caregiving, social support and quality of life of informal caregivers of patients with cerebral palsy”. The purpose of this study was to investigate the mediating function of social support in the association between the sleep states of parents of children with cerebral palsy (CP) and the care burden they bear. Caregiving often involves physical, emotional, and financial strain, and caregivers can experience a significant impact on their own well-being. Social support plays a crucial role in alleviating the burden on caregivers. Healthcare professionals, family members, friends and community resources are major support system. Tools used to assess social support: Social Support Questionnaire (SSQ). (16)

6. **(Lily L. Dyson, 1997).** conducted a study on “Fathers and mothers of School-age children with developmental disabilities: Parental stress, family functioning and social support”. A review of literature on parents of children with disabilities highlights that while fathers and mothers of children with developmental disabilities experience similar levels of stress, social support, and family functioning as parents of typically developing children, they report significantly higher stress related to their children's condition. This stress is linked to caregiving demands, concerns about the child's future, and societal challenges. Both parents’ stress impacts family functioning, with stress levels being associated with their perceptions of family dynamics. The involvement of both parents in caregiving tends to improve family functioning, emphasizing the importance of support systems for these families. (22)

3.Methodology

Research Design:

A cross-sectional study design

Study Setting:

This study was conducted in NIEPMD, Muttukadu, Chennai, Tamil Nadu.

Sampling Technique:

Convenience sampling technique was used for this study.

Sample Population:

Parents of children with developmental disabilities.

Sample Size:

Sample size(n) is equal to 61

Variables:

- Dependent variable –Sleep quality and Participation
- Independent variable-Parents of children with developmental disabilities.

Selection Criteria:

Inclusion Criteria:

- Parents of children diagnosed with any developmental disability of 2-9 years of age.
- Parents from both gender
- Parents those who are able to read Tamil or English.

Exclusion Criteria:

- Parents of disabled children who have separate caregivers for their children and Parent should not have any kind of disability.

Description of Tools Used

Pittsburgh Sleep Quality Index (PSQI):

The PSQI is a self-report tool designed to assess sleep quality and disruptions. It consists of 19 items divided into

7 components, which measure aspects such as subjective sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of sleep medications, and daytime dysfunction over the past month. Based on the responses, sleep quality is classified as either "good" or "poor."

Scoring interpretation:

The overall score ranges between 0 to 21.

Participation Scale (P-scale):

The Participation Scale is a new 18-item interview-based instrument designed to assess perceived problems in major life domains. The scale will allow people affected by leprosy, disability, or other stigmatized conditions to quantify their participation restrictions. The Participation Scale addresses eight of the nine major life domains defined in the World Health Organization's International Classification of Functioning, Disability, and Health (ICF), which was published in 2001. The Participation Scale can be administered in less than 20 minutes on average. The majority of questions ask the respondent to compare themselves to an actual or hypothetical 'peer', someone who is similar to them in every way except the disease or disability. The respondent is asked if they believe their level of participation is equal to or lower than that of their peer (s). If a potential problem is indicated, the respondent is asked how big a problem it is to them ('no problem (1)', 'small problem (2)', 'medium problem (3)', 'large problem (5)').

Data Collection and Analysis Procedure

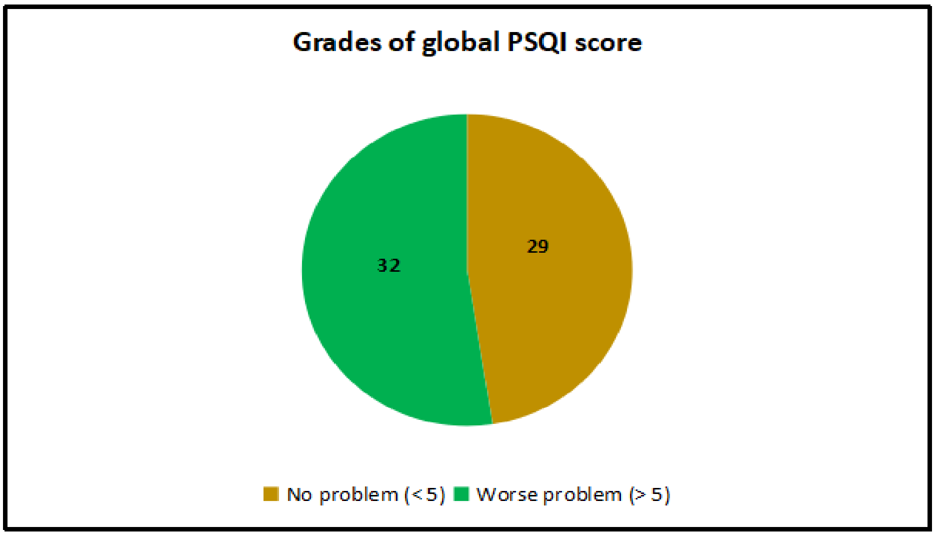
A convenient sampling method was used for this study, which took place at the National Institute of Empowerment for Persons with Multiple Disabilities (NIEPMD). The purpose of the study was explained to the participants, and from the 65 individuals who expressed interest, 61 were selected based on the inclusion criteria. Written consent was obtained from all participants before the study began. They were assured that their information would remain confidential, and their demographic details were collected. The 61 participants then completed the Participation scale (p-scale) and Pittsburgh sleep quality index (PSQI) with the help of an interviewer, and the scores were recorded. Finally, the collected data were analyzed and interpreted.

The collected data were summarized by using the Descriptive Statistics: frequency, percentage; mean and S.D. The Independent sample “t” test was used to compare participation restriction, and global PSQI score; between males and females. The Likelihood ratio test was used to compare difference in proportions. To find the relation between participation restriction, and global PSQI score; the Pearson correlation coefficient: (“r”) was used. The p value < 0.05 was considered as significant. Data were analyzed by using the SPSS software (SPSS Inc.; Chicago, IL) version 29.0.10

4.Results

Table 1: Frequency & percentage distribution of sleep quality among parents of children with developmental disabilities

		Frequency	%
Global PSQI score	No problem (< 5)	29	47.5
	Worse problem (> 5)	32	52.5

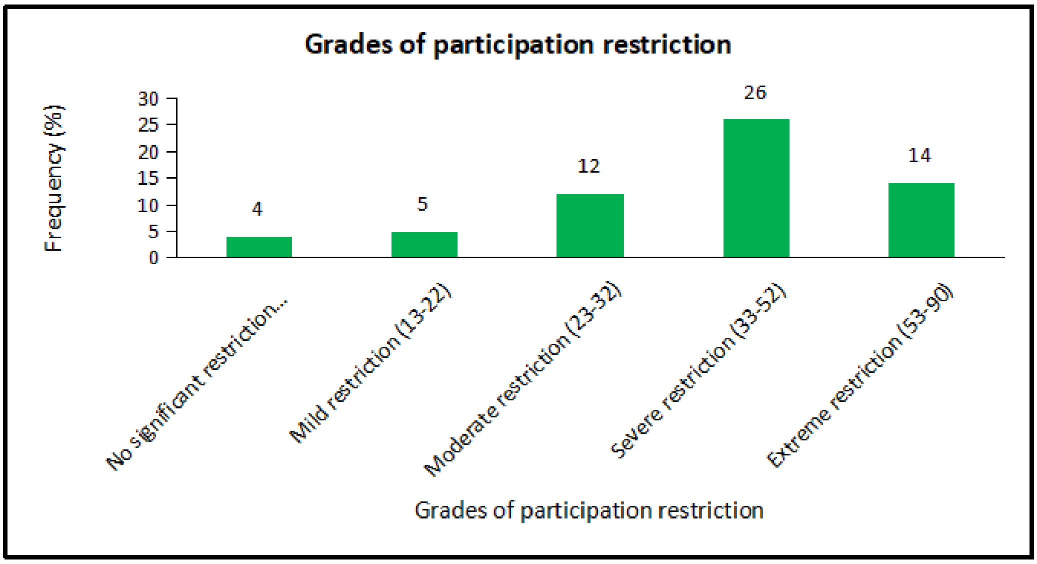


Graph 1: The following graph represents the frequency and percentage distribution of sleep quality

The study included total of 61 participants. The above-mentioned table and graph reveal that out of 61 samples, (47.5%, n=29) had no problem and (52.2%, n=32) had worse problem which was assessed by Pittsburgh Sleep Quality Index (PSQI).

Table 2: Frequency & percentage distribution of participation among parents of children with developmental disabilities.

		Frequency	%
Grades of participation restriction	No significant restriction (0-12)	4	6.6
	Mild restriction (13-22)	5	8.2
	Moderate restriction (23-32)	12	19.7
	Severe restriction (33-52)	26	42.6
	Extreme restriction (53-90)	14	23



Graph 2: The following graph represents the frequency and percentage distribution of participation restriction.

The above-mentioned table and graph reveal that out of 61 samples, about 6.6% of parents of children with developmental disabilities had no significant restriction, 8.2% had mild restriction, 19.7% had moderate restriction, 42.6% had sever restriction and 23% had extreme restriction which was assessed by Participation scale(p-scale).

Table 3: Descriptive Statistics for participation restriction, and global PSQI score

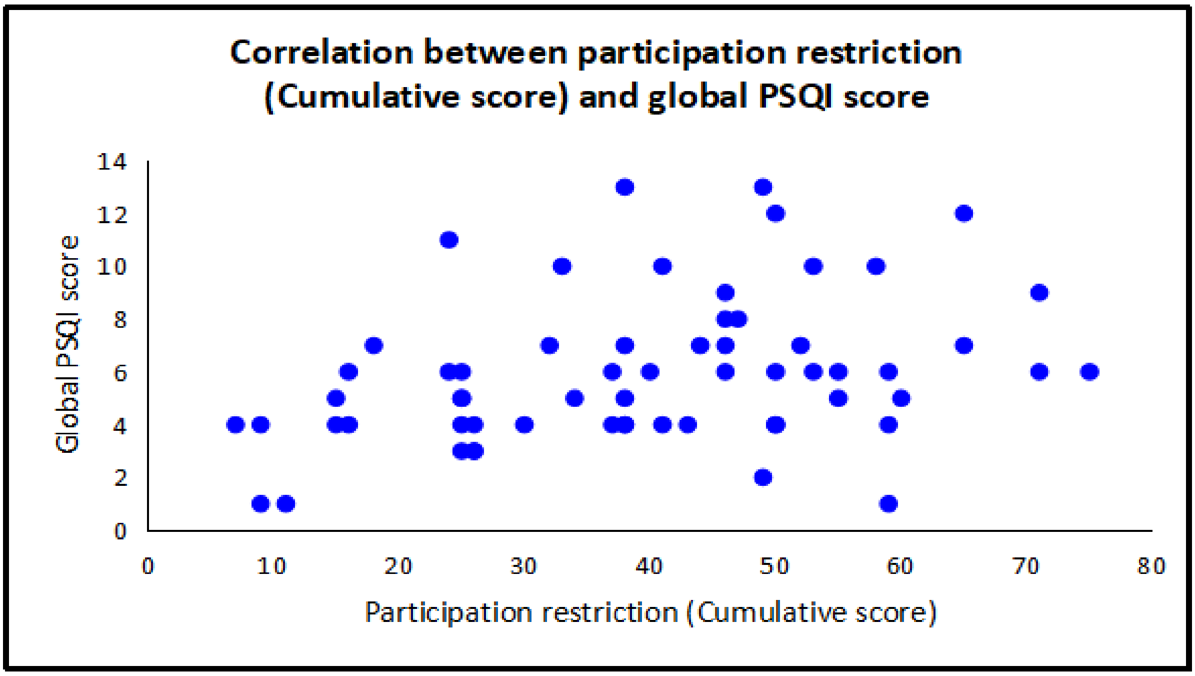
	Range	Mean	S.D.
Participation scale (Total score)	7 to 75	39.48	16.91
Global PSQI score	1 to 13	5.98	2.82

Shows that the participation score among parents of children with Developmental disabilities measured using the Participation scale(p-scale) varies from a lower score of 7 to a higher participation restriction score of about 75, it shows the mean value of participation scale score of about 39.48 and standard deviation 16.91, that shows the participation Score deviates among the mean value. The Global PSQI score among parents of children with Developmental disabilities measured using the Pittsburgh Sleep Quality Index varies from a lower score of 1 to a higher stress score of about 13, it shows the mean value of Global PSQI score of about 5.98, and standard deviation 2.82, that shows the Global PSQI Score deviates among the mean value.

Table 4: Correlation between participation restriction, and global PSQI score

		Global PSQI score
Participation restriction (Total score) Global PSQI Score	"r"	0.346
	p value	0.006*

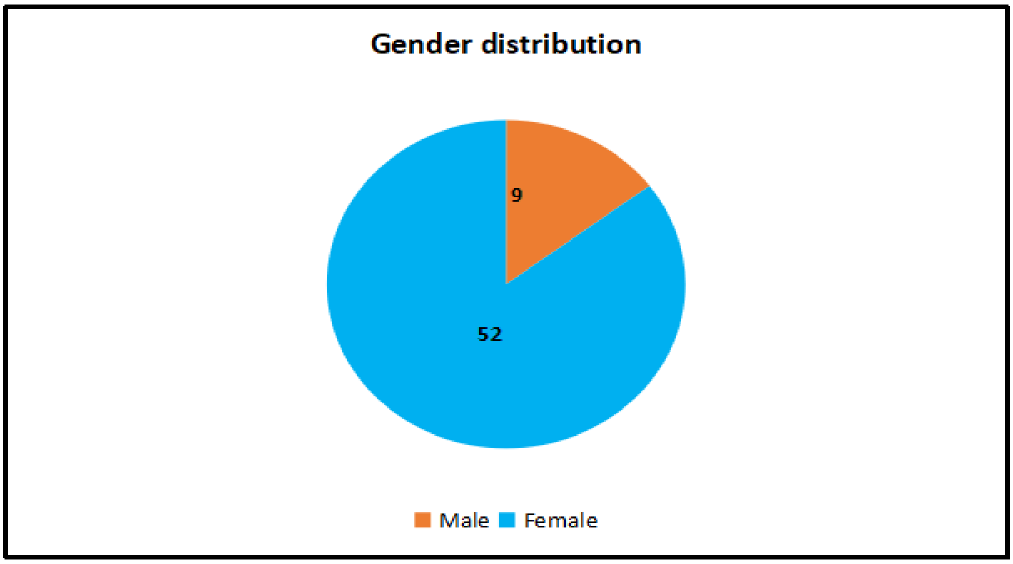
(“r” = Pearson correlation coefficient; * Significant) The Pearson correlation coefficient: (“r”) was used to find the relation between participation restriction, and global PSQI score. There was a positive correlation ($p < 0.05$) between participation restriction, and global PSQI score.



Graph 3: Relationship between sleep quality and participation restriction.

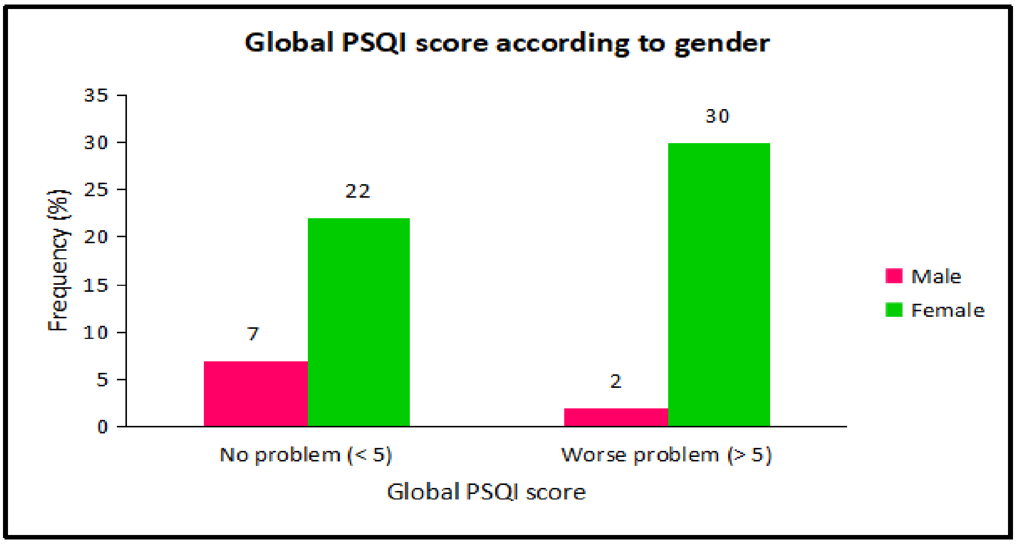
Table 5: Frequency & percentage of gender distribution among parents of children with developmental disabilities.

Gender	Male	9	14.8
	Female	52	85.2



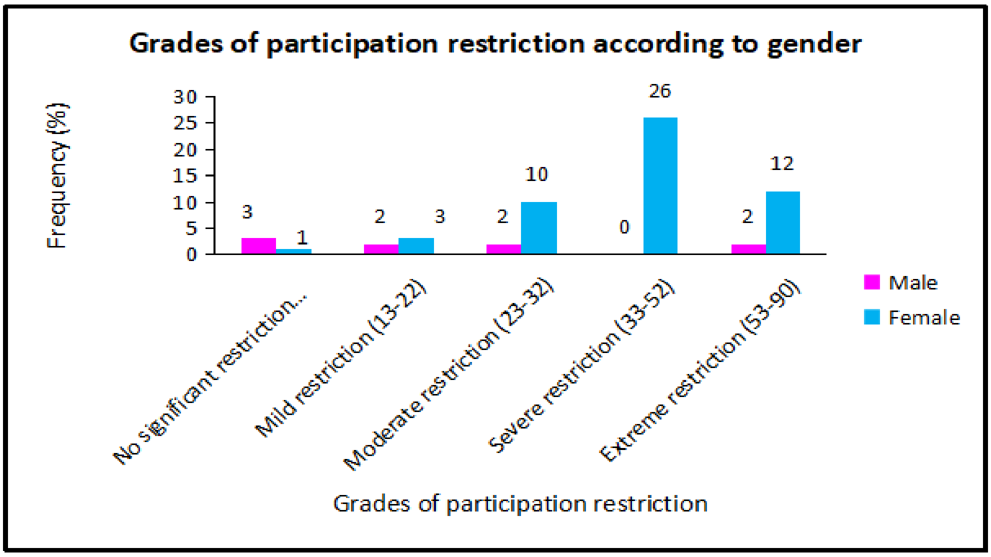
Graph 4: The following graph represents the frequency and percentage of gender distribution among parents of children with developmental disabilities.

A study included a total of 61 participants, with the majority being female (85.2%, n=52), while only (14.8%, n=9) were female.



Graph 5: Global PSQI score according to gender.

The above graph is the graphical representation of the distribution of sleep quality among the participants.



Graph 6: Grades of participation restriction according to gender

The above graph is the graphical representation of the distribution of Extent of participation among the participants.

Table 6: Comparison of participation restriction, and global PSQI score according to gender

		Mean	S.D.	"t"	p value
Participation restriction (Total score)	Male	25.56	20.73	-2.83	0.006*
	Female	41.88	15.13		
Global PSQI score	Male	3.89	2.03	-2.52	0.014*
	Female	6.35	2.79		

(“t” = Independent sample “t” test; * Significant)

The Independent sample “t” test was used to compare participation restriction, and global PSQI score according to gender. There was a difference ($p < 0.05$) in the participation restriction as well as global PSQI score; between males and females. [Table – 7]

Table 7: Association of grades of participation restriction, and sleep quality with gender

		Gender				Likelihood ratio	p value
		Male		Female			
		n	%	n	%		
Grades of participation restriction	No significant restriction (0-12)	3	33.3	1	1.9	17.52	0.002*
	Mild restriction (13-22)	2	22.2	3	5.8		
	Moderate restriction (23-32)	2	22.2	10	19.2		
	Severe restriction (33-52)	0	0	26	50.0		
	Extreme restriction (53-90)	2	22.2	12	23.1		
Global PSQI score	No problem (< 5)	7	77.8	22	42.3	4.03	0.045*
	Worse problem (> 5)	2	22.2	30	57.7		

(* Significant)

The Likelihood ratio test was used to find the association of grades of participation restriction, and sleep quality with gender. There was an association ($p < 0.05$) between grades of participation restriction, sleep quality (Global PSQI score) and the gender.

5.Discussion

This section discusses about the results of the study interpreted from the statistical analysis. The present study was conducted to assess the sleep quality and extent of participation among parents of children with developmental disability. Based on the inclusion criteria, 61 parents were selected as participants by convenient sampling and participated in the study. From the analysed data, the results have been obtained and explained in this chapter.

The result of the present study with reference to Table 1 revealed that out of 61 parents(n=29) 47.5% of parents of children with developmental disabilities had good sleep quality, (n=32) 52.2% had poor sleep quality.

Table 2 shows that out of 61 parents (n=4) 6.6% of parents of children with developmental disabilities had no significant restriction, (n=5) 8.2% had mild restriction, (n=12) 19.7% had moderate restriction, (n=26) 42.6% had sever restriction and (n=14) 23% had extreme restriction.

Table 3 Displays the mean value of the participation scale score of about 39.48, and the standard deviation of 16.98, and the mean value of global PSQI score is 5.98, and the standard deviation of 2.82 it shows that parents score deviates among the mean value. Thus, the result indicated majority of the parents had moderate levels of sleep problem and participation restrictions. This could be probably due to Constant caregiving demands and Concerns about the child's well-being produced greater difficulties in fulfilling the parental role. This finding of the present study was consistent with the findings of researcher (Francesco Craig, 2016) which indicated that parents of children with neurodevelopmental disabilities experience more care burden than those of children who have typical development.

Table 4 showed that the Pearson correlation coefficient ("r") was used to find the relation between overall quality of sleep quality and participation restriction. The findings were $r=0.346$, $p=0.006$, ($p<0.05$). Therefore, it was indicated that there was a positive correlation between the scoring of sleep quality and participation as the value is less than 0. This in turn showed a positive correlation between poor sleep quality and participation restriction. Thus, the alternative hypothesis "there is a significant correlation between sleep quality and participation among parents of children with developmental disabilities" was retained. The reason for the finding could be due to the combination of emotional, physical, and practical challenges associated with raising a child with special needs leading to various sleep disturbances. The result of the present study was consistent with the findings of the study **(**Chi- Wen-Chien,2019) which concluded that poor sleep quality affects the participation among children's.

Table 5 explains about the gender distribution of participants in this study. The study includes 9 male and 52 female constituting 14.8% and 85.2% of the study respectively, also this was represented using pie chart in graph 4.

Table 6 it is observed that there was significant relationship ($p>0.05$) between the participation restriction as well as global PSQI score; between males and females.

Table 7 it is observed that there was an association ($p < 0.05$) between grades of participation restriction, sleep quality (Global PSQI score) and the gender.

6.Conclusion

The present research aimed to assess the sleep quality and participation among parents of children with developmental disabilities and explore the correlation between and sleep quality and participation hence this study concluded that;

- A majority of parents experienced moderate participation restriction, with a significant proportion reporting poor sleep quality.
- A positive correlation was found between scores on the Global PSQI score a participation score suggesting that poor sleep quality is associated with participation restriction among parents caring for children with developmental disabilities.
- This research shows there was a difference ($p < 0.05$) in the participation restriction as well as global PSQI score; between males and females.

7.Limitations

- Unequal gender distribution.
- Samples collected from a particular small place.

8.Recommendations

- This study can be done with a large sample size because the incidence and prevalence of Developmental Disability is high.
- This study can be conducted among various culture in variety of places to be generalized.
- This study can be conducted among caregivers of other population also.

Declaration by Authors

Ethical approval: Approved

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Conflict of interest: The authors declare no conflict of interest**.**

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