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Burden, Quality of Life and Depression in Caregivers of Children with Attention Hyperactivity Disorder and Caregivers of Children with Normal Mental Health

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Abstract

The study investigated the relationship between Burden, Quality of life, and depression among Caregivers with ADHD and normal children. 80 Parents of ADHD diagnosed by the professional of the state government, 80 parents of children not with any mental illness, age ranging between 30 to 45 years of age, residing in Aizawl, were selected using purposive random sampling to serve as a sample. The study used the Zarit Burden Interview (Zarit, Reever & Bach-Peterson, 1980), Quality of Life (WHO Quality of Life-BREF, 1996) and the Beck Depression Inventory (BDI) (Beck, Steel & Brown, 1996) for the collection of data. Results showed that caregivers of ADHD showed lower Quality of Life compared to caregivers of normal children while the former showed higher mean scores on Depression and Burden. Quality of life had a negative relation with depression and burden, and burden significantly predicted depression and quality of life which invites the need to pay attention to caregivers to Children with ADHD by giving psychological care and other amenities.

Keywords*: depression, quality of life, anxiety, caregiver, children*

Introduction

It is common for individuals to experience mental problem from time to time when faced with life difficulties. However, these challenges may develop into mental illnesses problems signs and symptoms persists and cause frequent stress and impair the ability to function. Mental illness and mental health disorders are often used interchangeably, to describe a wide range of mental health conditions, that impact mood, thinking and behaviour. The Diagnostic and Statistical Manual of Mental Disorders (DSM), Fifth Edition recognises 300 mental illnesses (Peterson, 2019), and categorized these different mental disorders into five distinct groups: neurodevelopmental disorders, internalizing disorders, externalizing disorders, neurocognitive disorders, and other disorders.

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Among the many mental illnesses, Attention-deficit/hyperactivity disorder (ADHD) falls under neurodevelopmental disorders according to the DSM-5 classification. Attention-deficit/hyperactivity disorder (ADHD) is a neurobehavioral disorder marked by inattention, impulsivity, and hyperactivity. ADHD have heterogeneous and variable impacts on functioning and daily activities for affected children and their caregivers. In the paediatric population, Attention-deficit hyperactivity disorder (ADHD) has a prevalence of 5 to 7.1% (Polanczyk et al., 2007; Willcutt, 2012). Its symptoms, inattention, hyperactivity, and impulsivity symptoms, results in clinically significant impairment to the patient (APA, 2013).

Caregiver burden refers to the psychological distress experienced by individuals who provide care. It is specific to the care and varies from anxiety and depression to other emotional and more general responses (Given et al., 2001). Overall burden of psychiatric morbidities that are linked to poor child outcomes, policies and strategies primarily benefit children with neuro-developmental disorders (Mahbub et al., 2022). There is a paucity of research concerning the effects of parenting children with NDD and their vulnerability to different psychopathologies in India (Purva et al., 2022). Because the mother's health directly affects the health of her kid and the family, it is crucial to close this gap (Asfana & Komal, 2023).

The concept of Quality of Life (QoL) generally refers to an individual's subjective perception of physical, emotional, and social well-being (Göz et al., 2007) which encompasses both cognitive (satisfaction) and an emotional component (happiness). Quality of Life (QoL) can be affected by various proximal factors, such as family and friendships, as well as distal factors, including socioeconomic and cultural influences. The presence of a chronic illness is considered one of the most significant risk factors for lower QoL scores (Harpin et al., 2005; Göz et al., 2007; Xiang et al., 2009; Kim et al., 2014).

The caregivers' capacity to take care of both the person they are caring for and themselves may be impacted by carer burnout. Long-term carers are more likely to experience burnout and be more susceptible to physical and mental health issues (Richard & Paula, 2008). The caring responsibilities of children with disabilities may cause them to put off routine check-ups with their physician or, worse, to put off the necessary treatment for a persistent medical condition. If symptoms of mental health disorders, such as anxiety or depression, remain untreated, there is a consequent decline in the quality of life for both the individuals affected and their loved ones. The health of their loved one may also deteriorate. Extreme stress and sadness brought on by burnout can, in rare and extreme circumstances, endanger the lives of carers (François & Janie, 2021).

Having a child with developmental disabilities constitutes a crisis event, how parents respond to the associated stresses of raising their child with special needs depends upon a multitude of factors that influence their ability to cope. These factors include their interpretation of the crisis event, the

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family's sources of support, community resources, and family structure. Additionally, the personality characteristics of the family members, their financial status, educational level, problem-solving skills, and spirituality significantly affect a family's coping capacity. Strong marital relationships and social support are also critical determinants of parental adjustment (Thwala et al., 2015; Fazil et al., 2004). Parents of children with autism and ADHD encounter a set of distinct set of challenges related to providing care for their children. Depending upon the nature and severity of the disability, the child may necessitate substantial personal care and monitoring to ensure their wellness and safety, with parents typically serving as the primary caregivers. Given other responsibilities that parents generally have in maintaining stability for their family, the additional obligation of providing extensive care for their child indefinitely may challenge parents' ability to maintain balance in their own lives. This may lead to stress for parents, potentially compromising their capacity to effectively care for their child.

Review of Literature

The study conducted by Cussen et al. (2012) assesses the QoL and depression among 202 primary caregivers of children with ADHD, comparing them to a control group. The findings indicated that parents of children with ADHD poorer family QoL and higher levels of parental depression and anxiety disorders. Similarly, Akvardar and colleagues (2006) compared the QoL scores between patients with psychiatric disorders and a control group, revealing that individuals with mental reported lower satisfaction compared with patients with normal controls. Craig and colleagues (2020) conducted a systematic review of coping strategies employed by parents of children with attention deficit hyperactivity disorder (ADHD).

The presence of ADHD significantly impacts not only the patients but also their family members who provide care (Harpin, 2005). Caring for a child with ADHD can lead to family, marital, and parental problems, diminish parenting efficacy, and elevate parental stress levels (Danckaerts et al., 2010). Additionally, it is often accompanied by feelings of guilt which increase vulnerability to depression (Johnston & Mash, 2001) and result in diminished quality of life (Faraone et al., 2005; Desidério et al., 2010). The caregivers' capacity to take care of both the person they are caring for and themselves may be impacted by carer burnout. Long-term carers are more likely to experience burnout and be more susceptible to physical and mental health issues (Richard & Paula, 2008). The caring responsibilities of children with disabilities may cause them to put off routine check-ups with their physician or, worse, to put off the necessary treatment for a persistent medical condition. The quality of life declines for them and their loved one if mental health symptoms like anxiety or depression are not treated. The health of their loved one may also deteriorate. Extreme stress and sadness brought on by burnout can, in rare and extreme circumstances, endanger the lives of carers (François & Janie, 2021).

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Statement of the Problem

Behavioural issues in children adversely affect family adaptation, including quality of life and psychological well-being. Parents may experience feelings of helplessness, overwhelm, and fear in response to such behaviours, often leading them to question their parenting abilities and experience guilt over perceived inadequacies. Parents of children with ADHD face distinct challenges in providing care for their children.

In the Indian context, mothers often assume primary responsibility for raising and caring for a child with a disability. Given the additional responsibilities mothers typically bear in maintaining family stability, the ongoing care required for their child may strain their ability to maintain personal balance. This situation can lead to parental stress, potentially compromising their capacity to effectively care for their child. Parents employ various positive and negative coping strategies to manage this psychological stress. Notably, significant differences in coping behaviours have been observed among parents with varying marital and socioeconomic statuses.

Numerous studies have demonstrated that quality of life (QoL) may be compromised due to the presence of ADHD (Harpin et al., 2005; Sawyer et al., 2002; Akvardar et al., 2006; Cussen et al., 2012). However, there is a paucity of research examining QoL among ADHD caregivers (Andrade et al., 2016). To address this research gap, the present study aims to explore the coping mechanisms of parents of children with ADHD, with the objective of promoting positive coping strategies and assisting these parents in identifying supportive resources.

Objectives: The study set forth objectives based on the literature available as under:

1) To determine any variations in Psychological Quality of life and Depression between caregivers of children with ADHD and those with normal mental health.
2) To examine the association between depression and Psychological Quality of Life among caregivers of children with ADHD.
3) To examine the predictability of Psychological Quality of Life from Depression among caregivers with ADHD and parents of normal mental health.

Hypotheses: In consistent with the study's objectives, the following hypotheses have been formulated for the current research:

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1) Caregivers of children with ADHD and caregivers of children with normal mental health will not differ in terms of Psychological Quality of life and Depression.
2) There will be no significant positive correlation between Psychological Quality of life and Depression.
3) There will be no significant predictability of Depression on Psychological Quality of life among caregivers of children with ADHD and caregivers of children with normal mental health.

Methodology

Sample

The study sample consisted of 160 Mizo caregivers comprised of 80 caregivers of ADHD and 80 caregivers of children with normal mental health. The caregivers of children with ADHD were identified and selected from those whose children had been diagnosed with ADHD and were receiving treatment at the Department of Psychiatry at Kulikawn Hospital, as well as from special schools, the Child Guidance Centre, the District Early Intervention Centre, and private clinics in Aizawl, Mizoram. The caregivers of children with normal mental health were selected to closely match their counterparts in terms of socio-demographic variables, with both groups comprising individuals aged 25 to 50 years. The samples from both groups were well-matched on socio-demographic variables such as age, ecological background (urban and rural), educational level, and other factors, to facilitate a comparative analysis of psychological quality of life and depression.

Tool Used

1. ***Socio-Demographic Profile (Lalawmpuia, 2021):*** The instrument was specifically developed by Lalawmpuia (2021) for the purpose of screening, with the aim of controlling confounding demographic variables and ensuring accurate representation in accordance with the study's design. It encompasses data on socio-demographic variables, including age, sex, religion, education, marital status, residence, and occupation of the participants.
2. ***Informed Consent Form (Lalawmpuia, 2021).*** It was developed by Lalawmpuia (2021) to secure informed consent from participants following the provision of information regarding the current study.
3. ***WHO Quality of Life-BREF (1996):*** The World Health Organization's quality of life assessment, developed by the WHOQOL group, is designed for cross-cultural applicability. It comprises a total of 26 questions. The internal consistency coefficient for the domains ranges

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from 0.70 to 0.75. The the test-retest reliability coefficient at the item level varies from 0.41 to 0.79.

4. ***Beck Depression Inventory (BDI) (Beck, Steer& Brown, 1996):*** The instrument was developed to assess the severity of depression and comprises 21 items, each rated on a 4-point scale. It demonstrates a Cronbach's alpha of 0.92 and a validity coefficient of 0.98 (Beck et al., 1996). The test-retest reliability was determined, yielding an average correlation of 0.93.

Design

A correlational design was employed to discern the pattern of variations befalling caregivers of ADHD children and children of normal mental health to examine significant differences between the groups and the relationship between the variables under investigation and regression analysis to ascertain predictability.

Procedures

The required psychological tests were collected and made necessary preparation, and ready for use**.** The parents of ADHD parents' samples were randomly selected from the Department of Psychiatry at Kulikawn Hospital, various special schools, the Child Guidance Centre, a private clinic, the district early intervention centre, and the education department of Aizawl-Mizoram. Conversely, parents of children without ADHD or mental illness were selected from different regions of Aizawl to ensure a well-matched comparison with the parents of children with ADHD. All necessary permissions were obtained from the relevant authorities. Confidentiality was maintained, and informed consent was obtained from parents and participants in accordance with the manual and the APA code of ethics for research.

Results

Psychometric adequacy check

The test scales were constructed for other cultures and needed to be checked its applicability to the targeted population. For which, the normality, reliability and homogeneity were checked as presented in Table-1.

Table 1

Normality (Mean, SD, Kurtosis, Skewness), Reliability and homogeneity for the Zarit Burden Interview, Quality of Life and Beck Depression for the samples

Statistics	PTSD	Insomnia	Depression

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Normality	**Mean**	35.15	34.73	15.65
	SD	5.32	4.14	3.34
	Kurtosis	-0.75	0.74	-0.78
	Skewness	-0.77	0.87	0.76
Reliability coefficient		.80	.84	.81
Test of homogeneity (Levenes F statistics)		.75	.67	.74

The reliability of the tools used was checked for internal consistency using Cronbach's alpha. The result divulged a consistent pattern of response indicating that the three measurement tools are a reliable instrument for measuring Burden, Quality of Life and Depression among the target population.

Homoscedasticity was checked using Levene's test to discern whether the distribution of variances in Burden, Quality of Life and Depression are equal across the two caregiver groups. The result imparted a non-significant F statistic ($p>.05$) which indicates that we cannot reject the null hypothesis thereby indicating the similarities of the distributions.

Objective-1: To determine any variations in Psychological Quality of life and Depression between caregivers of children with ADHD and those with normal mental health.

An Independent t-test was employed to determine the significant difference between caregivers with ADHD and normal children on Burden, QoL and depression which is presented in Tables-2 &3.

Table 2

Descriptive Statistics (Mean, SD, Kurtosis and Skewness) for the Caregivers to ADHD and normal mental health children on Burden, Quality of Life and Depression of the samples

Independent Variables	**Statistics**	**Dependent Variables**		
		Burden	**Quality of Life**	**Depression**

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Caregivers of ADHD	**Mean**	29.74	13.25	16.78
	SD	3.794	2.316	3.29
	Kurtosis	-0.73	-.87	-0.85
	Skewness	0.78	-0.76	0.79
Caregivers of Normal children	**Mean**	25.50	17.48	13.53
	SD	4.84	0.847	0.71
	Kurtosis	0.93	-0.57	-0.73
	Skewness	0.78	85	0.33

Table 2 shows the descriptive statistics on Burden, Quality of Life and Depression separately for caregivers of ADHD and normal children along with Skewness and Kurtosis statistics. The skewness and kurtosis statistics showed that the distribution for caregivers of ADHD and normal children on all three scales approximates normal distribution. Caregivers of ADHD have a higher mean score than caregivers of normal children on the Burden and Depression scales. On the other hand, Caregivers of normal children scored higher mean on Quality of Life compared to caregivers of ADHD children. Although subsequent analysis would reveal the significance of differences in their mean scores, it is noteworthy that Caregivers of ADHD may have a higher burden imposed upon them, and may show depressive symptoms compared to their counterparts.

Table 3

Independent sample t-test for Caregivers of ADHD and Caregivers of Normal children on Burden, Quality of Life and Depression.

Variables	Mean difference	T	df	Sig (2-tailed)
Burden	4.24	2.46	158	.000
Quality of Life	-4.23	-3.25	158	.000
Depression	3.25	2.65	158	.000

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Table-3 showed the independent t-test result for discerning differences between Caregivers of ADHD and Caregivers of Normal children. Results for the Burden scale were statistically significant indicating that ADHD caregivers have more weight in terms of the burden imposed upon having children with ADHD. The overall quality of life was also significantly lower among caregivers of ADHD (Moshe et al., 2017). The impact of caregiving for individuals with ADHD on quality of life is comparable to that associated with other mental health conditions and severe physical disorders. An increase in symptom severity and impairment is predictive of a diminished quality of life (Marina et al., 2010). In contrast, Depression was significantly higher among Caregivers of ADHD (Hui Wen el al., 2021). Results suggested not accepting hypothesis 1.

Objectives -2: To examine the association between depression and Psychological Quality of Life among caregivers of children with ADHD.

The Pearson Correlation was used to examine any significant relationship between burden, Qol and Depression among the samples, and presented in Table-4.

Table 4

Showing Pearsons' Correlation between Burden, QOL and Depression

Dependent variables	Quality of Life	Depression
Burden	-.45**	.51**
Quality of Life		-.47

** = significant at .01 level

The correlation between the three variables was estimated using the Pearson correlation coefficient. There was a moderately significant negative correlation between Burden and Quality of Life (r^2=-.45; p<.01) but a positive relationship between Burden and Depression (r^2=.51; p<.01) There was a statistically significant positive correlation between total burden of care and total psychological distress among studied caregivers (Miriam et al., 2023) while Quality of Life and Depression (r^2= -.47; p<.01) had a negative relationship at significant levels . Results suggested not accepting hypothesis 2. The severity of children's ADHD symptoms has a detrimental impact on parents' quality of life, family functioning, and family burden. (Calvo et al., 2021).

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Objectives -3: To examine the predictability of Psychological Quality of Life from Depression among caregivers with ADHD and parents of normal mental health.

The simple linear regression analysis was used to investigate the prediction of burden on QoL and Depression and is presented in Table-5.

Table 5

Predictability of Quality of Life and Depression from Burden

Criterion	Dependent variable	B
Burden	Quality of Life	-.21
	Depression	.27

Regression analysis was employed to examine the prediction of Burden on Quality of Life and Depression which revealed that Burden predicted 21% of Quality of life and 27% of depression among the samples. Research indicates that numerous parents of children with ADHD report elevated stress and that they deal with increased familial and marital discord. These parents often report heightened parental stress, feelings of guilt, vulnerability to depression, increased alcohol consumption, and a reduced quality of life (QoL), particularly in the domains of emotional and family activity (Shuliweeh et al., 2024). Results suggested not accepting hypothesis 3.

Discussion & Conclusion:

Results revealed that Caregivers of ADHD scored a higher mean score on Burden and Depression while a lower mean score was observed on Quality of Life. There is a variation between caregivers of children with ADHD and normal mental health on depression and anxiety (Cussen et al., 2012). Caregivers of children with ADHD reported low family Quality of life. Caregivers of ADHD reported lower levels of satisfaction than patients with normal controls, according to the QoL scores (Akvardar et al., 2006). Furthermore, taking care of a child with ADHD increases stress levels for parents and decreases parenting efficacy, hence attracting marital, family, and parental issues (Danckaerts et al., 2010). The present study also confirmed that there was difference between Caregivers of ADHD and normal children on Burden, Quality of Life and Depression. It is crucial that

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Caregivers of ADHD have proper remedy from burden and depression due to caregiving children having difficulty in attention and hyperactive (Saeid et al.,2018). The overall Quality of Life was also lower than caregivers of normal children, it is imperative to prepare a module to improve their life satisfaction level. The correlation between Burden and Quality of Life showed that increasing burden among caregivers of ADHD could decrease the Quality of Life and increase levels of depression (Juana et al.,2019).

Limitation

The present study was unable to include single parents in its analysis. The small sample size employed in this study restricted the generalizability of the findings and limited the examination of psychological variables.

Significance of the study

This study has made a significant contribution to understanding the burden, quality of life, and depression experienced by caregivers, an area previously unexplored. It underscores the necessity for psychological interventions to support them.

Suggestion

While the present study has yielded significant findings, it is not without limitations, which suggest several considerations for future research. First, the inclusion of a larger sample size is recommended to enhance the reliability of the findings and facilitate the generalization to the target population. Second, incorporating a broader range of mental health patients for comparative analysis could provide more comprehensive insights into the caregiver burden associated with mental health conditions. Third, the inclusion of additional mental health symptoms would contribute to a deeper understanding of psychological issues, thereby informing the development of prevention and intervention strategies for the target group. Furthermore, there is a pressing need for more research on the psychosocial well-being of parents and caregivers of children with disabilities.

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

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