### THE BURDEN OF CARING AND PARENTING STYLES USED BY CAREGIVERS OF CHILDREN WITH MENTAL DISORDERS AT BUTABIKA NATIONAL PSYCHIATRIC REFERRAL HOSPITAL. A CROSS-SECTIONAL STUDY.

Violet Nakabiria,\*, Jolly Magulub

<sup>a</sup> School of Psychiatric Clinical Officers, Butabika, Kampala, Uganda. <sup>b</sup> School of Applied Sciences, Mildmay Institute of Health Sciences, Kampala, Uganda.

#### Abstract

#### **Introduction:**

Caring for children and adolescents with mental disorders brings a unique set of stressors and challenges to the whole family. This study aimed to establish the proportion of caregiver burden for children with mental disorders and the parenting styles used by their primary caregivers.

#### Methodology:

This was a cross-sectional study: 74 caregivers for children (1-17 years) receiving care at Butabika Hospital were enrolled using a consecutive sampling method. Caregiver burden was measured using Zarit Burden Interview (ZBI) and parenting styles were assessed using the Parenting Styles and Dimensions Questionnaire (PSDQ). Data was analyzed descriptively, using SPSS v25.

#### **Results:**

The mean age of caregivers was  $4.1\pm 9.7$  years and were taking care of children with Attention Deficit and Hyperactivity Disorder 20(27.0%), psychotic disorder 16(21.6%), Bipolar Affective Disorder15(20.3%) and autism spectrum disorder 14(18.9%). The mean caregiver burden score was 41.8  $\pm 21.5$  and the majority 24(32.4%) had moderate to severe burden with 79.7% at risk of developing depression. The authoritative parenting style was the most preferred (mean =  $4.1\pm 1.0$ ). The study revealed that there is no significant relationship between caregiver burden and parenting styles used.

#### **Conclusion:**

There is a substantial caregiver burden among caregivers of children with mental disorders with many at high risk for depression.

#### **Recommendations:**

Caregivers using alternative methods of parenting such as permissive and authoritarian need training to adopt the recommended parenting method. We recommend that health workers take a lead role in embracing parent-centered programs to support and relieve parenting stress such as triple P (positive parenting program) for those entering the caregiving role. Further studies to determine the association between parenting styles and the caregiver's quality of life need to be done to adapt culturally acceptable interventions.

*Keywords:* caregiver burden, parenting styles, primary caregivers, depression, mental disorders, children and adolescents, Submitted: 2023-07-17 Accepted: 2023-07-07-19

#### 1. INTRODUCTION.

Mental health-related problems among children and adolescents have increased over the course of time and these present a major impact on the present and future of these young people (Campelo et al., 2014). Compared to mentally healthy children, children with mental disorders require a lot of time, affection, and attention (Brehaut et al., 2011). World health organization (WHO) recommends community-based care for children with mental illness, therefore, the care giving role is left to parents or relatives at home (World Health Organization, 2001). This is common in Uganda, especially for caregivers of children with mental illness (Ministry of Health, 2017). The caregivers encounter quite several challenges in different dimensions such as economic, psychological, emotional, and social (Sharif et al., 2020).

In Sub-Saharan Africa, a systematic review study reported a moderate to severe burden (Addo et al., 2018). In Kenya, 39.7% experienced moderate to severe burden (Molebatsi et al., 2017), 79% of the caregivers were at risk of depression (Mbugua et al., 2011) and 56.7% overall prevalence of depression among caregivers was reported in Ethiopia (Minichil et al., 2019).

As a result of the stress, parents of children with mental disorders tend to engage in parenting styles that are less conducive to the proper development of their children (Goodman & Glenwick, 2012), and higher parenting stress is associated with more permissive parenting (Likhitweerawong et al., 2022).

However, there is a paucity of information about the burden of caring and the parenting styles used by caregivers of children and adolescents with mental disorders in Uganda. Therefore, the study aimed at determining the burden of caregivers for children with mental disorders and the parenting styles used.

#### 2. METHODS.

#### 2.1. Study design and site.

The researcher used a cross-sectional research design and employed quantitative research methods. The study was carried out in the children's ward at Butabika National Psychiatric Referral Hospital of Uganda from February to April 2022; a government hospital located in Butabika, southeastern part of the city, in Nakawa Division, adjacent to the northern shores of Lake Victoria, Kampala district, Buganda region. The location is approximately 12 kilometers by road, east of Kampala's central business center. It is located on plot 2 Kirombe-Butabika road. The child and adolescent mental health services at the hospital are delivered through the children's ward with both outpatient and inpatient services. The age limit for patients in the children's ward is 17 years. Children's ward provides its services from Monday to Friday for outpatients with a major clinic day on Wednesday while inpatient services are provided throughout the week.

#### 2.2. Study population.

The study was conducted among primary caregivers of children with any form of psychiatric disorder aged 1 to 17 years. Children with epilepsy without a psychiatric comorbidity were excluded.

#### 2.3. Sample size.

The sample size was determined using the formula below;

$$n_{\circ} = \frac{Z^2 pq}{e^2}$$

Where = is the percentage occurrence of caregiver burden among primary caregivers of children with mental disorders which was 39.7% (Molebatsi et al., 2017). To get the appropriate sample size for a study of 100 (sampling frame) children and adolescents (1-17years) with mental disorders at the children's ward in July 2020 (DHIS, 2020), a **ftnite population correction for proportions formula** is used as below to adjust the sample size (Israel, 1992).

$$\frac{\frac{n}{2} = \frac{n}{n}}{1 + N}$$

<sup>\*</sup>Corresponding author.

Email address: nviolet125@gmail.com (Violet Nakabiri)

Where, N = 100 (children with mental disorders).  

$$n = \frac{368}{1 + (\frac{368 - 1}{100})}. = 79.0$$

The appropriate sample size was 79, however, 74 participants were recruited due to covid-19 restriction movements.

#### 2.4. Sampling procedure.

A non-probability sampling technique specifically a consecutive sampling technique was used in which respondents who meet the inclusion criteria and were conveniently available at the time of data collection were approached to take part in the study until the required sample size was achieved. Therefore, every patient who had finished seeing their clinician was approached for screening.

#### 2.5. Inclusion and Exclusion Criteria.

#### 2.5.1. Inclusion criteria.

Caregivers of children aged 1 to 17 years with mental disorders attending the children's ward in Butabika National Referral Mental Hospital. The considered psychiatric disorders were in the category of Neurodevelopmental disorders, learning disorders, hyperkinetic and behavioral disorders, psychotic disorders, anxiety disorders, substance abuse, and eating disorders. Children with comorbidities of general medical conditions such as epilepsy, cerebral palsy, HIV/AIDS, etc. were included.

#### 2.6. Definition of variables.

### 2.6.1. The independent variables of the study were;

Psychiatric Disorders in children and adolescents (learning disorders, hyperkinetic and behavioral disorders, psychotic disorders, neurodevelopmental disorders, anxiety disorders, substance abuse, and eating disorders.

### 2.6.2. The dependent variables of the study were:

Caregiver burden among primary caregivers of children with mental disorders and parenting styles used by caregivers of children with mental disorders.

#### 2.7. Data collection method.

The interview method of data collection was used.

#### 2.8. Research instruments.

The Zarit Burden interview was administered to collect data on the burden of care for primary care givers of children with mental disorders. The Zarit Burden Interview is a popular caregiver self-report measure for the burden of caregiving. The revised version of it contains 22 items; each item on the interview is a statement that the caregiver is asked to endorse using a 5-point scale whose response options range from 0 (never) to 4 (nearly always) (Bachner & O'Rourke, 2007). Item scores were added up to give a total score ranging from 0 to 88, with higher scores indicating a higher burden.

The parenting styles were assessed using the Parenting Styles and Dimensions Questionnaire (PSDQ). The parenting styles and dimensions questionnaire is a self-report instrument designed to measure authoritarian, authoritative, and permissive parenting styles used by caregivers of children ages 4 to 12. Each item on the scale was evaluated with the 6-point Likert scale whose scores range from 1(never) to 6(always). At the end of each section, the scores were added up and the total was divided by the number of questions in that section to find the calculated score. The highest-scored parenting style of the three was considered the most used parenting style for the participant.

#### 2.9. Reliability and Validity.

The Zarit Burden interview was used in Uganda to determine the caregiving burden among family caregivers of people with mental illness. In the study, each item on the Zarit Burden index was endorsed by more than 70% of the study participants (Ainamani et al., 2020).

The confirmatory factor analysis of PSDQ showed the result met the criteria standard for adequacy of fit. The parenting style and dimensions questionnaire (PSDQ), in line with psychometric requirements, had good reliability and validity and was stated useful as a tool to evaluate

parenting styles (Fu et al., 2013) with the values of kappa for inter-rater reliability between 0.625 and 0.884 (p < .05); and the values of retest reliability were between 0.537 and 0.832 (p < .05);

#### 2.10. Data collection procedure.

The interviewer administered a questionnaire to the respondent who had finished seeing the clinician. All the questionnaires were translated into the language best understood by the respondents before data collection and then translated back to English to check their consistency

After receiving the approval letter and permission from the hospital management, a caregiver who has already seen the clinician educated him/her about the topic and also informed him/her of the relevance of the study which enabled them to make an informed decision to participate in the study. After their consent, the researcher interviewed one on one participant and the procedure was repeated until the required sample size was achieved.

#### 2.11. Data management.

The collected questionnaires were kept safely in a lockable file cabinet and the key was kept by the researcher to ensure confidentiality. Data were coded, entered into a Microsoft Excel spreadsheet, and kept on a password-protected computer, a copy was kept on flash disks in soft copy for backup to revisit in case of any reference.

#### 2.12. Data analysis.

Data were analyzed using a statistical package of social sciences software and presented in the form of tables, graphs, and pie charts using percentages and frequencies as well as chi-square tests.

The burden of caring for children was determined by the total score and graded according to "o-20 little or no burden", "21-40 mild to moderate burden", "41-60 moderate to severe burden", and "61-88 severe burden". A cut-off of 24 was considered to have a risk for depression (Bachner & O'Rourke, 2007).

For parenting styles used by caregivers of children with mental disorders, the mean score, and

standard deviation for each parenting style were calculated separately to allow comparison and variations between parenting styles. The one with the highest mean score was considered the most used parenting style for caregivers of children with mental illness.

For the relationship between parenting caregiver burden and parenting styles, Fishers' exact test was used.

#### 2.13. Bias.

The PI was working at the data collection site however 2 research assistants participated in data collection. The required sample size was not reached due to COVID-19 restrictions however 93.7% of the data was achieved.

#### 3. RESULTS OF THE STUDY.

A total of 79 caregivers approached, one for each child were approached for the study from February to April 2022. Of these 74 caregivers agreed to take part in the study.

#### 3.1. Socio-demographic characteristics.

According to the table below, the mean age of the participants is 4±9.7 years which ranges from 22 to 71 years. The majority 63(85.1%) of the respondents were parents to the affected child. A significant number 30(40.5%) of caregivers were male, and 54(73.0%) married/cohabiting. Most 29(39.2%) attained secondary education, 55(74.3%) were paid/ self-employed and only 11(14.9%) unemployed. The majority (27.0%) of the children being taken care of had ADHD (**Table 1**).

### 3.2. The burden of primary caregivers of children with mental disorders.

Using the ZBI score, the mean score for caregiver burden is 41.8±21.5 and this is indicative that majority of the caregivers suffered from moderate to severe burden (**Figure 1**).

According to the study findings, 13(17.6%) of the respondents had little or no burden, 20(27.0%) had mild to moderate burden, 24(32.4%) had moderate to severe burden and 17(23.0%) had severe burden (Figure 1).

Table 1: Shows the socio-demographic characteristics of the participants (n=74).

Variable Ca	tegory	N=74, n(%)		
Age		Mean = $41.18 \pm 9.7$ Range		
		(22 to 71)		
Relationship to patient	Parent	63(85.1%)		
	Sibling	5(6.8%)		
	Aunt/Uncle	4(5.4%)		
	Other	2(2.7%)		
Sex	Female	44(59.5%)		
	Male	30(40.5%)		
Marital status	Single/Unmarried	20(27.0%)		
	Married/Cohabiting	54(73.0%)		
Tribe	Muganda	48(64.9%)		
	Musoga	5(6.8%)		
	Munyankole	1(1.4%)		
	Others	20(27.0%)		
	No formal education	5(6.8%)		
Level of education	Primary education or less	24(32.4%)		
Level of education	Secondary education	29(39.2%)		
	Tertiary / further education	16(21.6%)		
Employment status	Paid / self employed	55(74.3%)		
	Unemployed	11(4.9%)		
	Student	1(1.4%)		
	House wife / husband	6(8.1%)		
	Retired	1(1.4%)		
	ADHD	20(27.0%)		
	ASD	14(18.9%)		
Diagnosis of the	Psychotic disorder	16(21.6%)		
patient	BAD	15(20.3%)		
patient	ID	4(5.4%)		
	Anxiety disorder	4(5.4%)		
	Conversion disorder	1(1.4%)		

#### 3.3. Risk for depression using ZBI.

A cutoff of 24 total points and above is considered to be a risk for depression in caregivers; a score of 23 and below is considered to be no risk for depression.

The study revealed that 59(79.7%) of the study participants are at a risk of developing depression and only15(20.3%) are not at risk of developing depression (Figure 2).

## 3.4. Parenting styles used by primary caregivers of children with mental disorders.

Most of the caregivers of children with mental disorders preferred Authoritative style of parenting with a mean score of 4.1± 1.0, followed by authoritarian with a mean score of 2.2± 0.9 and the least preferred was permissive parenting style with a mean score of 2.0± 1.1. The results showed that caregivers of children with mental disorders are less permissive but more authoritarian in their parenting (Table 2).

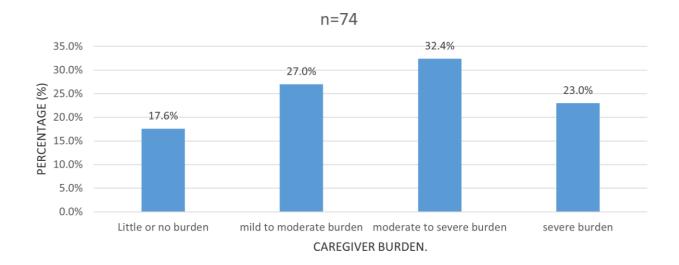


Figure 1: Showing the severity of the caregiver burden.

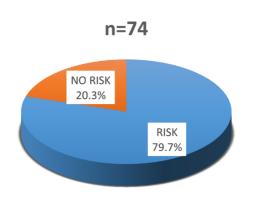


Figure 2: Showing the risk for depression in caregivers of children with mental disorders using ZBI.

Table 2: Showing the mean score of the preferred parenting styles.							
Mean score for parenting styles.							
	Permissive	Authoritative	Authoritarian				
Mean	2.0	4.1	2.2				
Std. Deviation	1.1	1.0	0.9				

## 3.5. Relationship between primary caregiver burden and parenting styles.

Using the Fishers exact test there was no significant relationship established between caregiver burden and parenting styles.

There was no significant relationship between caregiver burden and parenting styles depending on the Fishers exact test results (Table 3).

#### 4. DISCUSSION.

### 4.1. The burden of primary caregivers of children with mental disorders.

These results closely relate with that of other studies such as in Kenya where 39.7% of the participants reported moderate to severe burden (Molebatsi et al., 2017) and the mean caregiver burden was 45. The results of this study are also closely related to the findings of Molebatsi et al.,

Table 3: Showing the relationship between caregiver burden and parenting styles.

Caregiver burden category	Parenting styles Authoritative parenting style n (%)	Permissive parenting style n(%)	Authoritarian parenting style n(%)	Fishers' exact test
Little or no burden	13(17.6%)	0(0.0%)	0(0.0%)	p = 0.189 Phi-
mild to moderate burden	20(27.0%)	0(0.0%)	0(0.0%)	crammers V=0.188
moderate to severe burden	22(29.7%)	1(1.4%)	1(1.4%)	
severe burden	10(13.5%)	4(5.4%)	3(4.1%)	

(2017) in other measures of burden that are mild to moderate (27.0% and 30.6%) and severe burden (23.0% and 21.8%) respectively. This is because of the similarities in the study design and closely related sociodemographic variables.

However, they don't correlate with the findings of Dada et al., (2011) in Nigeria where the majority of the participants (41.3%) reported little or no burden and only 3.2% reported severe burden in comparison to the 23.0% in the current study. This may be due to the smaller sample size used in the current study compared to the larger sample size used in the Nigerian study and the differences in the difference in social and healthcare resources available in different countries.

#### 4.2. Risk for depression.

In this study, 79.7% of the study participants were at risk of depression and this compares with the results of the study of Mbugua et al., (2011) in Kenya where 79% of the caregivers were at risk for depression. This is because Uganda and Kenya almost have the same socio-economic status and living conditions. In addition, children with mental disorders require more caring and support psychologically, emotionally financially among others compared to normally developing children.

# 4.3. The parenting styles used by primary caregivers of children with mental disorders.

The caregivers of children with mental disorders displayed more use of the authoritative parenting

style than the authoritarian and permissive parenting styles. This is consistent with the results of (Clauser et al., 2021) in the USA, (Sabat et al., 2021) in the USA, (Tripathi, 2016) in India, (Moghaddam et al., 2013) in Iran, (Likhitweerawong et al., 2022) in Thailand where caregivers of children with mental disorders reported more use of authoritative parenting style even though the cultures are different. However, the results are inconsistent with the results of (Gau & Chang, 2013) and Gau et al., (2010) where caregivers reported more use of authoritarian parenting style. This is because caregivers of children with mental disorders in Butabika Hospital are psychoeducated about the condition of their children and the way to handle them and their behavioral disturbances and this starts immediately when the child is brought to the hospital. Those with ASD and ADHD undergo continuous parental training which helps them to cope with the behavioral problems of their children.

Contrary to other studies (Clauser et al., 2021) in the USA, (Hutchison et al., 2016), caregivers endorsed more use of authoritarian parenting style in comparison to permissive parenting style. However, the results are similar to those of (Tripathi, 2016) and (Hutchison et al., 2016) for normally developing children. This may be attributed to the behavioral problems associated with children with mental disorders for example in ADHD where children are involved in risky behaviors so parents tend to be more authoritarian

than permissive in their parenting.

### 4.4. The relationship between caregiver burden and parenting styles.

Much of the literature on parenting stress and parenting styles suggests that parents with higher levels of parenting stress employ more permissive and authoritarian parenting than authoritative parenting in caring for their children with mental disorders (Likhitweerawong et al., 2022). In contrast, the current study did not find the expected inverse relationship between parenting stress and authoritative parenting. In addition, there was no significant relationship between parenting stress and parenting styles (p = 0.189, V = 0.188) using Fisher's exact test. This could be because of the psychological sessions attended during the care of these children which emphasize more of the caregiver and coach role other than letting alone or playing the coach role.

#### 5. CONCLUSIONS.

Caregivers of children with mental disorders have moderate to severe burdens and are faced with a risk for depression. These caregivers prefer an authoritative parenting style but also implore an authoritarian parenting style. There is no significant relationship between caregiver burden and parenting styles preferred.

#### 6. STUDY LIMITATIONS.

A relatively small sample size of the study compared to the general population renders caution with generalization of the results of the study.

The study setting is typically urban; therefore, the results may not be an accurate representation of all caregivers of children with mental disorders in remote areas of Uganda.

In addition, hospital-based sampling might have excluded severely burdened caregivers who were unable to be present due to financial constraints.

#### 7. RECOMMENDATIONS.

Caregivers using alternative methods of parenting such as permissive and authoritarian should be educated about the recommended parenting method and its importance in the development of a child with a mental disorder by the clinicians. We recommend that health workers take a lead role in embracing parent-centered programs to support and relieve parenting stress such as triple P (positive parenting program) for everyone entering the caregiving role. Further studies to determine the association between parenting styles and the caregiver's quality of life need to be done to adapt interventions to our cultural setting.

#### 8. ABBREVIATIONS.

ADHD: Attention-deficit/ hyperactivity disorder; ASD: Autism spectrum disorder; BN-RMH: Butabika National Referral Mental Hospital; PDSQ: Parenting styles and dimensions questionnaire; WHO: World Health Organization; ZBI: Zarit Burden Interview.

#### 9. SUPPLEMENTARY INFORMATION.

Any additional data required will be availed as requested by the editors.

#### 10. ACKNOWLEDGMENTS.

We appreciate the Child and Adolescent ward team of Butabika Hospital for their support during the data collection phase of the study. We also thank the study participants who willingly entrusted us with their valued information.

#### 11. Authors' contributions.

VN conceived the idea, concept development and writing, translation of study tools, data collection, supervised data collection, developed the first draft of the manuscript, and protocol writing. JM participated in and supervised the concept writing, review, and editing of the original manuscript draft, and supervised data analysis.

#### 12. Funding.

The research was funded solely by the authors.

#### 13. Availability of data and materials.

All the data needed for this manuscript has been included. In case there is a need for clarification, the corresponding author can be contacted.

#### 14. Declarations.

### 14.1. Ethics approval and consent to participate.

The study received approval from the School of psychiatric clinical officers and institutional approval from Butabika National Referral Psychiatric Hospital. Unique identification participant codes were used to identify participants hence, no participant identifiers were captured at data entry to ensure their privacy and confidentiality. Written informed consent was obtained from all participants and the study adhered to the Human Subject Protection guidelines as well as the hospital guidelines for research.

#### 14.2. Consent for publication.

Not applicable

#### 15. Competing interests.

The authors have no competing interests.

#### 16. Publisher details:

Publisher: Student's Journal of Health

Research (SJHR)

(ISSN 2709-9997) Online

Category: Non-Governmental & Non-profit

Organization

Email: studentsjournal2020@gmail.com

WhatsApp: +256775434261

Location: Wisdom Centre, P.O.BOX. 148,

Uganda, East Africa.



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#### **Author biography**

Violet Nakabiri is a 25-year-old female from Makindye and a licensed Psychiatric Clinical Officer since 2022. She has worked under Makerere University College of Health sciences and Butabika National Referral Hospital as a Research Assistant on both mental health and general medical research projects. Violet is currently pursuing neuroscience specifically a clinical program in Electroencephalogram (EEG) under Neurotech EEG Institute (USA).