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Assessment of Caregiver Burden Amongst Parents of Children With Congenital Heart Disease in Two Tertiary Hospitals in Nigeria: A Cross- Sectional Study

Lilian Ezeuko

lilian.ezeuko@npmcn.edu.ng

University of Benin Teaching Hospital

Alaoma Kawa

Federal Medical Centre

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Abstract

Background

Caregiver burden is a multidimensional strain experienced by individuals caring for patients with chronic illnesses. Parents of children with congenital heart disease (CHD) often face significant emotional, financial, and social challenges, particularly in resource- limited settings. This study assessed caregiver burden among parents of children with CHD attending two tertiary hospitals in Nigeria and identified associated factors

Methods

A hospital-based cross-sectional study was conducted among 100 primary caregivers of children with CHD receiving follow-up care at the University of Benin Teaching Hospital (UBTH), Benin City, and Federal Teaching Hospital (FTH), Owerri. Data were collected using a structured socio-demographic and caregiver burden questionnaire comprising seven domains. Data were analysed using SPSS version 26.0. Descriptive statistics summarized the variables while Chi-square tests identified associations and predictors. Statistical significance was set at $p < 0.05$.

Results

The majority of caregivers were females (94%) and aged 31–40 years (54%). Most (96%) financed care through out-of-pocket payments. Overall, 41% of caregivers experienced moderate burden, and 26% severe burden. The emotional/psychological domain had the highest mean score (13.40 ± 5.27), followed by financial strain (8.57 ± 4.99) and uncertainty about the future (8.04 ± 4.17). No statistically significant associations were found between caregiver burden and socio-demographic or clinical variables.

Conclusion

Caregiver burden among parents of children with CHD is substantial, with emotional and financial strain predominating. Integrating psychosocial support and improving financial protection mechanisms are essential to enhance family-centered CHD care.

Introduction

Caregiver burden refers to the physical, psychological, social, and financial strain experienced by individuals who provide ongoing care to a person with a chronic illness or disability.[1] Amongst caregivers of children with congenital heart disease (CHD), this burden can be particularly profound due to the complex, long-term, and often unpredictable nature of the condition. Congenital heart disease is the

most common congenital anomaly worldwide, affecting approximately 8–10 per 1,000 live births.[2] It encompasses a wide spectrum of structural abnormalities of the heart and great vessels that arise during foetal development. These defects range from simple lesions, such as small septal defects, to complex and life-threatening conditions requiring multiple surgical interventions. Advances in diagnosis and treatment have significantly improved survival rates, shifting attention beyond mortality to the quality of life of affected children and their families.[3]

Globally, improvements in paediatric cardiology and cardiac surgery have led to increased survival into adolescence and adulthood for children with CHD.[3] The American Heart Association and the World Health Organization emphasize the importance of comprehensive, family-centered care for children with chronic illnesses.[4] As survival improves, the caregiving role often becomes prolonged and more demanding. Caregivers- particularly mothers- must manage frequent hospital visits, medication regimens, nutritional challenges, activity restrictions, and monitoring for complications such as heart failure or arrhythmias [(5)]. In resource-limited settings, these responsibilities are compounded by limited access to specialized cardiac services and financial constraints.[6]

Caregiver burden is multidimensional. Objective burden refers to tangible demands such as time spent providing care, financial costs, and disruptions to employment.[1] Subjective burden reflects emotional and psychological responses, including stress, anxiety, and depressive symptoms.[7] Caring for a child with CHD often involves navigating uncertainty regarding prognosis, coping with the stress of surgical procedures, and managing fears of sudden deterioration or death.[8] Recurrent hospitalizations may disrupt family stability and affect sibling well-being.[9]

Psychological distress is a significant component of caregiver burden in CHD. Studies have demonstrated higher levels of anxiety and depression among caregivers of children with complex heart defects compared to caregivers of healthy children.[7, 8] The period surrounding diagnosis and surgical intervention is particularly stressful, with parents frequently reporting shock, guilt, or self-blame.[8] Chronic stress may lead to caregiver burnout and impaired quality of life.[10] Financial burden is another critical dimension, particularly in low- and middle-income countries where health insurance coverage is limited.[6] The costs of investigations, medications, surgeries, transportation, and hospital stays can be overwhelming. In some families, one parent may reduce working hours or stop employment entirely to provide full-time care, resulting in income loss and increased economic strain.[6] This financial pressure may negatively affect access to care and adherence to follow-up appointments. Social isolation also contributes to caregiver burden. Caregivers may limit social interactions due to caregiving demands or concerns about exposing the child to infections.[9] Reduced social support can worsen psychological distress. Importantly, caregiver burden affects not only caregiver well-being but also child health outcomes. High stress levels have been associated with poorer treatment adherence and impaired parent–child interactions.[10] Conversely, psychosocial interventions, counselling, and support groups have been shown to reduce caregiver stress and improve coping strategies.[10] In Nigeria, where health

financing is largely out-of-pocket and social support systems are weak, the burden on caregivers may be greater than in high-income countries.[11] Yet, research on the caregiver burden of parents with children with CHD in sub-Saharan Africa remains sparse, with most available data originating from Western or Asian populations. Understanding caregiver burden is essential to guide psychosocial support programs, inform health policy, and improve holistic CHD care.

AIMS AND OBJECTIVES

General Aim

To assess the caregiver burden among caregivers of children with congenital heart disease

Specific Objectives

1. To determine the prevalence and severity of caregiver burden
2. To identify socio-demographic and clinical factors associated with high caregiver burden
3. To assess the psychological impact (anxiety and depression) among caregivers
4. To explore the relationship between caregiver burden and the child's profile (age, type of CHD, frequency of hospital visits)

Methodology

Study Area

The study was conducted at the UBTH Paediatric Cardiology Clinic in Benin City and the cardiology clinic of the Federal Teaching Hospital, Owerri.

The Cardiology clinic at UBTH Benin is a tertiary centre that receives referrals from all parts of Edo State and its environs and attends to patients from neighbouring states, including Delta, Kogi, Bayelsa, and Rivers States. The cardiology specialist clinic has about 250 patients registered.

FTH, Owerri, is a tertiary centre that receives referrals from all parts of Imo State and its environs and attends to patients from neighbouring states, including Anambra, Abia, Delta, and Rivers States. The facility has a total bed capacity of about 800 and provides both inpatient and outpatient services. The Cardiology clinic of FTH Owerri has about 70 patients registered in the clinic.

Study design

The study was a hospital-based cross-sectional descriptive study.

Study Population

Primary Caregivers (parents/ guardians) of children with CHD receiving follow-up care at the cardiology clinic of UBTH, Benin, and FTH Owerri made up the study population.

Sample Size

A total of 100 parents/guardians were recruited consecutively for this study

Ethical approval

/ Informed consent

This study was conducted in accordance with the ethical principles of the Declaration of Helsinki. Ethical approval was sought and obtained from the Human and Research Ethics Committee of University of Benin Teaching hospital, Benin city (NHREC-UBTH-HREC/24/12/2022B) and Federal teaching hospital Owerri (FTH/OW/HREC/VOL.1/212). The information and consent were given to parents/guardians to read and sign.

Methods

Two research assistants (1 registrar and 1 house officer) were trained to assist with this study in administering the questionnaires. The Caregivers of children with CHD were given clear and adequate information in English and/or Bini/Igbo Languages and allowed to make an informed decision.

Data Collection Tools

Structured Proforma developed specifically for this study was used to obtain information on;

- Socio-demographic details, child's clinical data
- Caregiver burden which comprised 7 domains (physical strain, emotional/psychological burden, financial strain, social/family impact, time/ role interference, treatment management, and uncertainty/future concerns). See Supplementary form I.

Data Analysis

The data were entered into the Excel spreadsheet. IBM Statistical Package for Social Sciences (SPSS) version 26.0 was used to analyse the data. As needed, frequency tables and figures were utilized to summarize the variables. Descriptive statistics were used to summarize the socio-demographic and clinical characteristics of children and their caregivers. Continuous variables such as age, burden scores, number of hospital visits, and medication costs were summarized using the mean and standard deviation for normally distributed data and the median with interquartile range for skewed data. Categorical variables were presented as percentages and frequencies. Caregiver burden scores were

computed by summing responses across the seven domains (physical strain, emotional/psychological burden, financial strain, social/family impact, time/role interference, treatment management, and healthcare navigation and uncertainty/future concerns). The total burden score was categorized into severity levels (minimal, mild, moderate, and severe) using a predetermined cut-off point. Bivariate analysis was performed to assess associations between caregiver severity and independent variables, including caregivers' socio-demographic characteristics (age, sex, education, socio-economic status). The Chi-square tests was used for associations between categorical variables. A p-value of < 0.05 was considered statistically significant.

Results

Socio-demographic characteristics of children with CHD.

Approximately two-third of the children with CHD were aged 0–5 years. Fifty-three percent (53%) were male, while 47% were female. Thirty-nine percent of the children with CHD were diagnosed between one month and one year of age. Forty percent of the children with CHD had 4–6 hospital visits in the last one year. Thirty-nine percent (39%) and 37% of the children with CHD had one and no hospital admissions since diagnosis, respectively.

Table Ia: Socio-demographic characteristics of children with CHD

Variable	Frequency (n = 100)	Percent (%)
Age	Median = 36 months	IQR = 54.75
0–5 years	66	66.0
6–10 years	25	25.0
10 years or older	9	9.0
Sex of child		
Male	53	53.0
Female	47	47.0
Age at diagnosis	Median = 7.5 months	IQR = 26
< 1 month after birth	26	26.0
1 month − 1 year	39	39.0
1 year − 5 years	22	22.0
After 5 years	13	13.0
Number of hospital visits in the last one year	Median = 4	IQR = 3
None	5	5.0
1–3	34	34.0
4–6	40	40.0
7–9	11	11.0
10 or more	10	10.0
Number of admissions since diagnosis	Median = 3	IQR = 1
None	37	37.0
One	39	39.0
Two	13	13.0
Three to six	11	11.0

Socio-demographic characteristics of caregivers of children with CHD.

More than half (54%) of the caregivers of children with CHD were aged 31–40 years. Most (94%) of the caregivers of children with CHD were female. Most (96%) of the caregivers of children with CHD paid for drugs and investigations out of pocket. The greater proportion (57%) of the caregivers of children with CHD had a tertiary education. Likewise, the greater proportion (43%) of the caregivers of children with CHD belonged to the middle socioeconomic class. Most (98%) of the primary caregivers of children with

CHD were also the respondents. The greater proportion (37%) of the caregivers of children with CHD reported an estimated monthly medication cost of 10,000 to 19,000 naira (50% of the caregivers spent above 10,000 naira).

Table Ib: Socio-demographic characteristics of caregivers of children with CHD

Variable	Frequency (n = 100)	Percent (%)
Caregivers' age		
30 years or younger	23	23.0
31–40 years	54	54.0
41–50 years	19	19.0
Older than 50 years	4	4.0
Caregivers' sex		
Male	6	6.0
Female	94	94.0
Source of funds for drugs/investigations		
Out-of-pocket	96	96.0
NHIS	4	4.0
Caregivers' highest level of education		
Primary	6	6.0
Secondary	37	37.0
Tertiary	57	57.0
Socio-economic status		
Upper class	18	18.0
Middle class	43	43.0
Lower class	39	39.0
Primary caregiver same as the respondent?		
Yes	98	98.0
No	2	2.0
Monthly medication cost	Median = 10,000	11,000
4,999 or less	18	18.0
5,000–9,999	24	24.0
10,000–19,999	37	37.0
20,000–39,999	10	10.0
40,000 or more	11	11.0

Prevalence of congenital heart disease.

Thirty-eight percent (38%) of all cases of congenital heart disease were ventricular septal defects (VSDs), 17% were tetralogy of Fallot (TOF), 14% were atrial septal defects (ASD), and 11% were patent ductus arteriosus (PDA).

Table II: Prevalence of CHD

Type of CHD	Frequency (n = 100)	Percent (%)
VSD	38	38.0
TOF	17	17.0
ASD	14	14.0
PDA	11	11.0
Complete AVSD	4	4.0
PDA, VSD	4	4.0
ASD, VSD	3	3.0
Others	9	9.0

Caregivers' burden score by domain.

The emotional/psychological domain had the highest mean score (13.40 ± 5.267) followed by financial strain (8.57 ± 4.997), uncertainty and future concerns (8.04 ± 4.168), time and role interference (7.73 ± 4.371), physical strain (6.63 ± 4.220), social and family impact (6.42 ± 4.669), and treatment management and healthcare Heart Disease (5.88 ± 3.574).

Table III: Caregivers' burden score by domain

Domain	Mean score	SD
Physical strain	6.63	4.220
Emotional/Psychological burden	13.40	5.267
Financial strain	8.57	4.997
Social and family impact	6.42	4.669
Time and role interference	7.73	4.371
Treatment management and healthcare navigations	5.88	3.574
Uncertainty and future concerns	8.04	4.168
Total	**56.67**	**24.901**

Overall burden of caregivers by severity

Forty one percent of the caregivers of children with CHD had a moderate burden, while 26% had a severe burden. See Fig. 1

Association between caregivers' Socio-economic profile and burden.

The greater proportion (18, 78.3%) of caregivers aged 40 years or above had a moderate/severe burden. However, the relationship between caregivers' age and severity of burden was not statistically significant (χ^2 = 1.827, P = 0.401). Likewise, the majority (30, 69.8%) of caregivers in the middle socioeconomic class had a moderate/severe burden. However, the relationship between caregivers' SES and severity of burden was not statistically significant (χ^2 = 1.303, P = 0.521).

Table IV: Association between Caregivers' Socio-economic Profile and Burden

Variable	Caregivers' Burden		χ^2 statistic	P-value
	Minimal/Mild	Moderate/Severe		
Caregivers' age				
Under 30 years	9 (39.1%)	14 (60.9%)	1.827	0.401
30–39 years	19 (35.2%)	35 (64.8%)		
40 years and above	5 (21.7%)	18 (78.3%)		
Caregivers' SES				
Upper class	8 (44.4%)	10 (55.6%)	1.303	0.521
Middle class	13 (30.2%)	30 (69.8%)		
Lower class	12 (30.8%)	27 (69.2%)		

Association between children's profiles and caregivers' burden.

The majority (21, 84.0%) of the caregivers of children with CHD aged 6–10 years had a moderate/severe burden. However, the relationship between children's age and severity of burden was not statistically significant (χ^2 = 5.608, P = 0.061). Likewise, the greater proportion (11, 84.6%) of children with CHD diagnosed after five years of age had a moderate/severe burden. However, the relationship between the child's age at diagnosis and severity of burden was not statistically significant (χ^2 = 2.290, P = 0.514). The greater proportion (17, 81.0%) of children with cyanotic CHD had a moderate/severe burden. However, the relationship between the category of CHD and the severity of burden was not statistically significant (χ^2 = 2.448, P = 0.191). The majority (28, 70.0%) of caregivers of children with CHD who had 4–6 hospital visits in the last one year also had a moderate/severe burden. However, the relationship between the number of hospital visits in the last one year and the severity of burden was not statistically significant (χ^2 = 0.312, P = 0.856).

Table V: Association between CHD Children's Profile and Caregivers' Burden

Variable	Caregivers' Burden		χ^2 or Fisher's exact statistic	P-value
	Minimal/Mild	Moderate/Severe		
Child's age				
0–5 years	27 (40.9%0	39 (59.1%)	5.608	0.061
6–10 years	4 (16.0%)	21 (84.0%)		
10 years or older	2 (22.2%)	7 (77.8%)		
Age at diagnosis				
< 1 month after birth	10 (38.5%)	16 (61.5%)	2.290	0.514
1 month – 1 year	13 (33.3%)	26 (66.7%)		
1 year – 5 years	8 (36.4%)	14 (65.6%)		
After 5 years	2 (15.4%)	11 (84.6%)		
Category of CHD				
Acyanotic	29 (37.2%)	49 (62.8%)	2.448	0.191
Cyanotic	4 (19.0%)	17 (81.0%)		
Number of hospital visits in last one year				
0–3	14 (35.9%)	25 (64.1%)	0.312	0.856
4–6	12 (30.0%)	28 (70.0%)		
7 or more	7 (33.3%)	14 (66.7%)		

Discussion

The results of this study illuminate the considerable caregiver burden faced by parents of children with congenital heart disease (CHD) in two Nigerian tertiary healthcare settings, where resource constraints amplify the challenges of managing a chronic paediatric condition. With 41% of caregivers experiencing moderate burden and 26% severe burden, the findings underscore a high overall prevalence of strain, consistent with global patterns observed in families navigating CHD.[12] The emotional/psychological domain was most prominently affected (mean score 13.40 ± 5.267), followed by financial strain (8.57 ± 4.997) and uncertainty about the future (8.04 ± 4.168), highlighting the interplay of psychological distress and economic pressures in low-resource environments.[13] These burdens are compounded by systemic factors, such as out-of-pocket payments for 96% of caregivers and frequent hospital visits (median 4 in the last year), which disrupt daily life and exacerbate role interference and social isolation.

The socio-demographic profile of the cohort provides critical insight into the vulnerabilities shaping caregiver experiences. Children were mostly (66%) less than 5 years, with ventricular septal defect (VSD) as the most common diagnosis (38%), aligning with worldwide epidemiological data where VSD accounts for a substantial portion of CHD cases.[14] Globally, the birth prevalence of CHD has stabilized at around 9.4 per 1,000 live births in recent decades, with mild lesions like VSD contributing significantly due to improved detection.[15] Caregivers were mostly female (94%) and aged 31–40 years (54%), reflecting gendered caregiving norms that often place disproportionate responsibility on mothers.[16] Despite a majority having tertiary education (57%) and middle socioeconomic status (43%), financial strain was evident, with half spending over 10,000 naira (approximately 7 US dollars) monthly on medications; this is significant for a country where 63% of the citizens are multidimensionally poor[17]. This paradox—relatively higher education yet persistent economic challenges—mirrors findings from other low- and middle-income countries (LMICs), where even educated families struggle with catastrophic health expenditures.[18]

The multifaceted nature of burden in this study resonates with prior research by Shahmansouri et al[19] in Iran, where emotional and financial domains predominate. Emotional/psychological strain, encompassing anxiety, depression, and grief, was the highest-scoring domain, consistent with qualitative accounts by Sabzevari *et al*[16] from mothers describing a "catastrophic burden" of internal struggles and social isolation. Financial strain, driven by out-of-pocket costs and lost productivity, aligns with study by Delaney *et al*[20] and Duru *et al*[21] in resource-limited settings, where families report perpetual worries about insurance and income dilemmas. Uncertainty and future concerns reflect the chronic, unpredictable trajectory of CHD, often leading to long-term psychological issues.[22] Lower scores in physical strain and treatment management suggest that while daily caregiving demands are manageable for many caregivers, cumulative emotional and economic tolls dominate.

No statistically significant associations emerged between burden severity and caregiver age, socioeconomic status, child's age, age at diagnosis, CHD category (acyanotic vs. cyanotic), or hospital visits. This pervasiveness of burden across profiles indicates that systemic healthcare barriers, rather than individual factors, may be primary drivers. However, trends toward higher moderate/severe burden in caregivers of older children (84.0% for 6–10 years) and those with later diagnoses (84.6% after 5 years) suggest cumulative stress from prolonged uncertainty.[23] Cyanotic CHD showed a non-significant trend toward higher burden (81.0%), supporting evidence that disease severity correlates with parental distress.[22] These patterns, though not reaching significance, echo longitudinal studies linking CHD complexity to elevated parental anxiety as reported by Roberts *et al*.[24]

The high burden levels in this Nigerian cohort parallel international findings, particularly in LMICs. In Iran, 47.2% of caregivers reported moderate-to-severe burden, with emotional and financial domains most affected.[19] A systematic review of mental health in parents of children with critical CHD revealed that 25–50% experience elevated depression/anxiety, and 30–80% severe distress, often persisting post-surgery.[12] In Africa, caregivers in Ethiopia and South Africa face similar financial hardships and

psychosocial distress, exacerbated by limited access to care.[18, 25] Chinese studies highlight higher depression and anxiety rates among CHD caregivers compared to those of healthy children, influenced by cultural and economic factors.[22] Coping strategies, such as spirituality and optimism, have been identified as buffers in Iranian and other families, suggesting resilience amid adversity.[26, 27] A meta-synthesis of parental coping in CHD emphasizes emotional responses, support systems, and avoidance strategies, varying by diagnosis timing and gender.[28]

These findings advocate for holistic, family-centred interventions in Nigeria, where only 4% utilized the National Health Insurance. Although Duru *et al*[21] reported that health insurance did not significantly reduce healthcare spending among the insured in their Nigerian study, expanding insurance coverage could alleviate financial strain, while integrating psychological support into paediatric cardiology clinics—such as routine screening and counselling, which might address emotional burdens.[29] Evidence supports psychoeducation, resilience-building, and peer support groups to enhance coping and quality of life.[27, 30] Multidisciplinary teams incorporating mental health professionals could monitor parental well-being, drawing from models that reduce distress in CHD families.[31] Policy efforts should prioritize financial aid, such as subsidies for medications and transportation, to prevent catastrophic expenditures.[32]

Conclusion

This study demonstrates that a significant proportion of caregivers experienced moderate (41%) to severe (26%) burden, indicating that caregiving for a child with CHD is associated with considerable strain. The emotional/psychological domain recorded the highest mean burden score, followed by financial strain and uncertainty about the future, underscoring the profound mental and economic impact of caring for a child with a chronic cardiac condition. The predominance of female caregivers further reflects the gendered nature of caregiving responsibilities within the Nigerian context. Despite relatively high levels of educational attainment among caregivers, nearly all (96%) relied on out-of-pocket payments for medical care, highlighting the inadequacy of financial risk protection mechanisms. Although no statistically significant associations were found between caregiver burden and socio-demographic or clinical variables, the consistently high levels of moderate-to-severe burden across different subgroups suggest that caregiver strain is pervasive and not confined to specific categories of caregivers or disease types. Overall, the findings emphasize that caregiver burden in CHD extends beyond medical management to encompass emotional distress, financial hardship, role disruption, and persistent uncertainty.

Recommendations

1. Routine psychological screening for anxiety, depression, and caregiver stress should be incorporated into paediatric cardiology clinics to mitigate emotional burden.

2. Expansion of the National Health Insurance Scheme (NHIS) to improve coverage for children with CHD is critical. Subsidizing medications, investigations, and surgeries would reduce catastrophic health expenditures.
3. Hospital – based peer support groups can provide emotional reassurance, shared coping strategies, and social connectedness among caregivers.
4. Structured counselling at the time of diagnosis and during follow-up visits may reduce uncertainty and improve caregiver coping and adaptation.

Limitations

1. The study is cross-sectional, which limits the ability to establish causal relationships between identified factors and caregiver burden.
2. The study was conducted in two tertiary centres, which may limit generalizability to caregivers in rural settings or primary/secondary healthcare facilities.

Declarations

Source of funding

Nil

Conflicts of interest:

Nil

Ethical approval and Consent to participate:

Ethical approval was sought and obtained from the Human and Research Ethics Committee of University of Benin Teaching hospital, Benin city (NHREC-UBTH-HREC/24/12/2022B) and Federal teaching hospital Owerri (FTH/OW/HREC/VOL.1/212). The information and consent were given to parents/guardians to read and sign.

Consent for publication:

Written informed consent was obtained from all individual participants (or their legal guardians) for publication of this study and its accompanying data.

Competing Interest:

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Author Contribution

Ezeuko Lilian: conceptualization, study design, data analysis and interpretation, drafting of the manuscript, and reviewing of the manuscriptKawa Alaoma: study design, literature review, data interpretation, and revision of the manuscriptNandom Benjamin: study design, literature review, data interpretation, and revision of the manuscript.Nwanebu Blessing: study design, literature review, data interpretation, and revision of the manuscript.

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Data Availability

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

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Figures

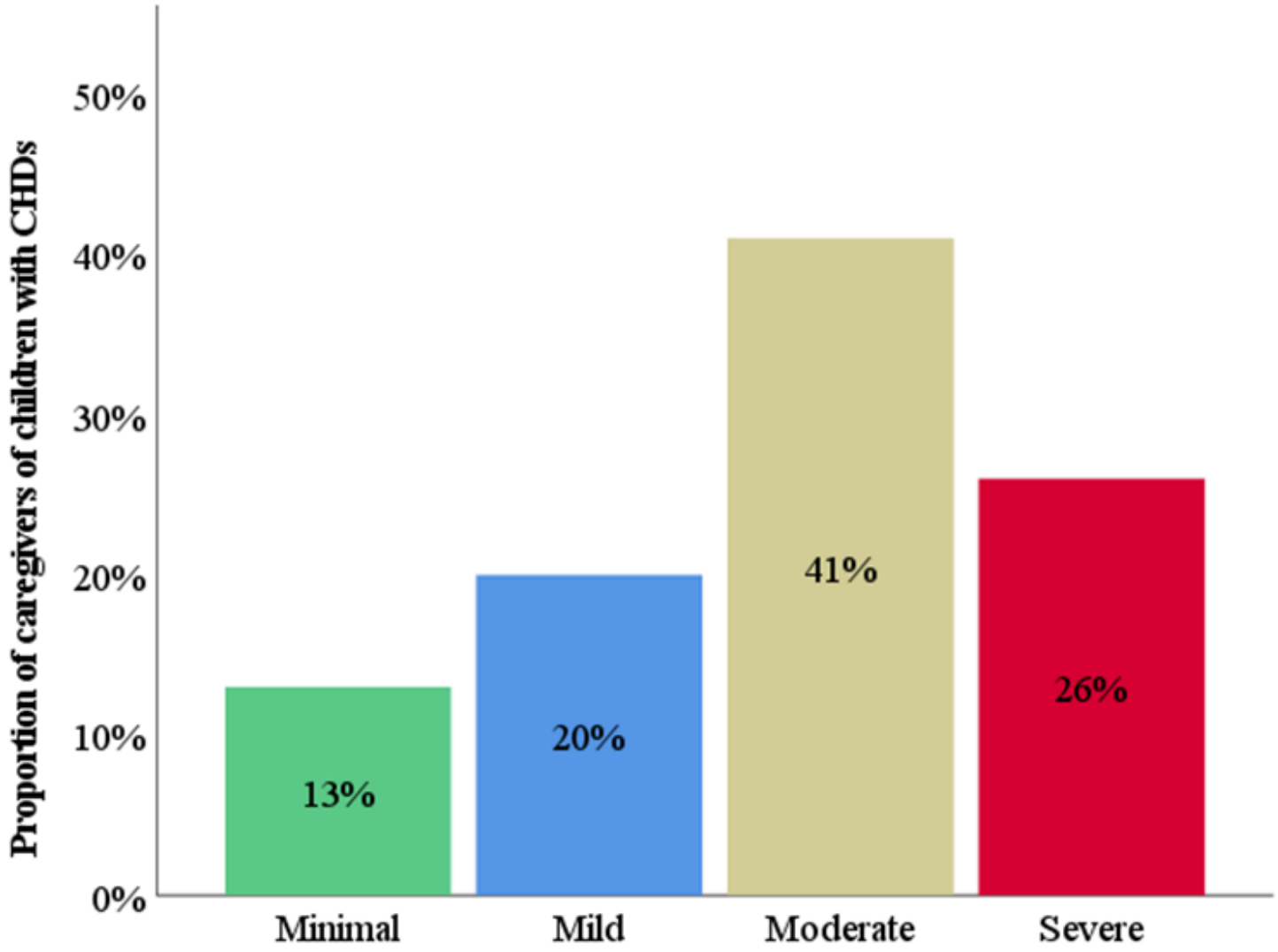


Figure 1

Overall burden of caregivers by severity

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