

Caregivers' burden of caring for children with chronic illnesses at a tertiary health facility in southern Nigeria

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Abstract

Background: The responsibilities perceived by caregivers of children with chronic diseases can impose significant burden on their physical, emotional and mental well-being.

Objective: To explore the burden of caregivers of children with chronic illnesses at a tertiary-care health facility in southern Nigeria, in order to devise effective ways of reducing them.

Methodology: It was a descriptive cross-sectional survey amongst parents/caregivers of children with chronic illnesses in the Children's Outpatient clinics /wards and emergency room, who presented for care and/or follow-up visits between October and December 2020. A validated Caregiver Burden Scale (CBS) that assesses the level of burden in five domains: general strain, isolation, disappointment, emotional involvement and environment, was used to obtain data. Caregivers' and the children's socio-demographic characteristics were also ascertained and compared with the level of burden. Data were analyzed using SPSS version 25.0. A p-value of < 0.05 was considered significant.

Result: A total of 109 caregivers completed the questionnaire. Half (n=55; 50.5%) of the caregivers were aged 30-39 years; 88 (80.7%) were females; 58 (53.2%) had post-secondary education and 51 (46.8%) were self-employed. Of the 109 children studied, 70 (64.2%) were males and the commonest diagnosis was sickle cell anaemia (SCA) (n=62; 56.9%) followed by Human Immunodeficiency Virus (HIV) disease (n=35; 32.1%). The age at diagnosis was 1-5 years in 70 (64.2%) of cases while 76 (69.7%) of them had received care for 1-5 years. The mean caregiving burden score was highest in disappointment (2.0) and lowest in the domain of isolation (1.5), while the overall mean score was 1.7 (SD=0.6). There was a statistically significant relationship between the caregivers' age and all the domains studied except the general strain, while the other socio-demographic variables had varying significance with the different domains of burden.

Conclusion: Severe burden of caregiving was experienced by more caregivers in the domains of disappointment and general strain while the isolation domain experienced the lowest frequency of caregivers with severe burden. Improving social support and advocacy to stakeholders, including the government to take over the financing of medical expenses of children with chronic diseases will reduce the burden of care experienced by their caregivers.

Keywords: Caregivers burden; Children; Chronic diseases; Tertiary facility

1. Introduction

Childhood chronic illness refers to conditions in paediatric patients that are usually prolonged in duration, do not resolve on their own, and are associated with impairment or disability [1]. The duration required for an illness to be

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defined as chronic is generally greater than 12 months, but this can vary, and some organizations define it by limitation of function rather than a length of time [2]. With advances in medicine, infant and child mortality especially from infectious causes has decreased in most areas of the world, resulting in increased number of children living with chronic illnesses, which affect 13-27% of children [3].

Chronic illnesses in childhood undermine children and their family, which is their main base of support, as coping with the diagnosis can cause physical and psychological strain, especially for the primary caregiver who most of the time is the mother [4,5,6]. They can pose several limitations in self-care functions such as feeding, dressing, bathing, and mobility, which can result in requirement for long-term care that far exceed the usual needs of normal children [7]. Affected children may require frequent hospitalizations and continuous and/or special care, which cause enormous material costs to their families, contributing to depleting the household's finances, especially in developing countries where there is high level of poverty and inequitable distribution of wealth and resources [5,8].

The responsibilities perceived by caregivers and the limitations induced by them and their family is referred to as caregiving burden [9]. It is defined as the caregivers' perceptions of the adverse effects of caregiving on their emotional, physical, mental, financial and social functioning, and this stems from the lack of established balance between care needs and other duties of the caregivers. It consists of subjective and objective dimensions. The objective caregiving burden is considered as the extent of time and effort required for supplying patients' needs including financial costs, family relations and social functions, while subjective caregiving burden is the degree of stress imposed on the caregivers when they face objective caregiving burden including mental, emotional and behavioral problems [10].

Literature indicates that providing care (or caregiving) to patients with chronic illnesses can negatively influence patient and caregiver's health outcomes [6-8,11]. Thus, it has been recommended that family caregivers confronted by significant psychosocial distress be targeted for effective interventions such as provision of information/ support, and promotion of positive coping styles among others, indicating the need to screen for those at risk [11,12].

Several instruments, which have been translated and validated for various languages, have been developed in order to measure the caregiver's level of burden, evaluating the variations in the burden of care for different illnesses [6].

In Nigeria, there are many different diseases affecting children that have a prolonged course and can lead to disability or impairment, including sickle cell anaemia (SCA), Human Immunodeficiency Virus (HIV)/ Acquired Immune deficiency Syndrome (AIDS), neurodevelopmental conditions, asthma, congenital heart disease, epilepsy and cancer, among others [5,7,8,13,14]. Though, the burden of caring for some of these diseases has been documented in some parts of the country, there is paucity of data in our region, the southern part of Nigeria. Thus, the present survey was conducted to explore the burden of caregivers who patronise our hospital with their children affected with chronic illnesses, in order to devise effective ways of reducing them.

2. Material and methods

This study was carried out at the University of Port Harcourt Teaching Hospital (UPTH), an 800-bedded federal tertiary health institution serving Rivers and the neighbouring States in southern Nigeria. It also serves as a general/referral centre for children in Port Harcourt and its environs.

It was a descriptive cross-sectional survey carried out between October and December 2020, amongst parents/caregivers of children who are being managed for various childhood chronic illnesses in the Department of Paediatrics, as they brought their children to the Children's Outpatient clinics /wards and emergency room for care and/or follow-up visits. The Children's Outpatient clinics are run on week days, while the wards and emergency room are opened 24/7. The department caters for children aged 0–17 years.

The instrument used for collection of data was the Caregiver Burden Scale (CBS), a 22-item validated scale that assesses the level of burden, referring to the domains of general strain (8 questions), isolation (3 questions), disappointment (5 questions), emotional involvement (3 questions) and environment (3 questions) [15,16]. The caregiver is asked to tick one of the four boxes (not at all, rarely, sometimes, often), with scores of 1 to 4 for each question. The mean score of caregiving burden in each domain was derived by calculating the mean score of items associated with that sub-scale. The total caregiving burden score was derived by calculating the mean scores of all items. A higher score indicated a greater burden. In this study, the answers "not at all" and "rarely" were categorized as low burden and "sometimes" and "often" as high burden. Then, caregiving burden was classified into two levels: low and high (severe).

In addition, information related to the caregivers and the child socio-demographic characteristics were ascertained and compared with the level of burden. The minimum wage in Nigeria is 30,000 Naira (1 USD=450 Naira).

Investigators sought the help of interpreters to interact with participants who did not speak and/or understand the English or Pidgin English languages.

Permission to conduct the study was obtained from the Ethics Committee of the hospital and informed consent from the parents/caregivers of affected children. Data were entered into a Microsoft Excel Spread Sheet and analyzed using SPSS version 25.0. A p-value of < 0.05 was considered significant.

3. Results

3.1. Socio-demographic characteristics of the Caregivers

A total of 109 caregivers caring for 109 children completed the questionnaire. Table 1 shows that 55 (50.5%) of the caregivers were aged 30-39years, 88 (80.7%) were females, 97 (89.0%) were married, 58 (53.2%) had post-secondary education, 51 (46.8%) were self-employed, 52 (47.7%) had an average monthly income of 31,000 – 150,000 naira.

Table 1 Socio-demographic Distribution of the caregivers.

	Frequency (n=109)	Percent
Age Group		
20 - 29 years	10	9.2
30 - 39 years	55	50.5
40 - 49 years	30	27.5
>50 years	14	12.8
Gender		
Male	21	19.3
Female	88	80.7
Marital status		
Single	4	3.7
Married	97	89
Separated	4	3.7
Widowed	4	3.7
Education		
No Formal education	4	3.7
Primary	6	5.5
Secondary	41	37.6
Post-Secondary	58	53.2
Occupation		
Farming	7	6.4
Public servant	15	13.8
Self-employed	51	46.8
Teacher	8	7.3
Trader	24	22
Unemployed	4	3.7
Average Monthly Income in Naira**		
<30000	34	31.2
31000 - 150000	52	47.7
151000 - 300000	23	21.1

**one dollar = 450naira

3.2. Distribution of Chronic disease condition in Parents/Caregivers

Among the caregivers, 76 (69.7%) had no underlying chronic illness while 25 (22.9%) had HIV disease (Table 2).

Table 2 Distribution of Chronic disease condition in Parent/Caregiver

Chronic disease	Frequency (n=109)	Percent
Hypertension	1	0.9
HIV disease	25	22.9
Physical disability	4	3.7
SCA	3	2.8
None	76	69.7

HIV: Human Immunodeficiency Virus; SCA: Sickle Cell Anaemia

3.3. Distribution of the diagnoses and Demographic characteristics of the Children

Of the 109 children studied, 70 (64.2%) were males, 62 (56.9%) had SCA while 35 (32.1%) had HIV disease. The age at diagnosis was 1-5years in 70 (64.2%) while 76 (69.7%) of them had received care for 1-5years (Table 3).

Table 3 Distribution of the diagnoses and Demographic characteristics of the Children.

	Frequency (n=109)	Percent
Diagnoses		
SCA	62	56.9
HIV disease	35	32.1
Cancer	8	7.3
Seizures	4	3.7
Child's gender		
Male	70	64.2
Female	39	35.8
Age at diagnosis		
1 - 5 years	78	71.6
6 - 10 years	19	17.4
> 10 years	12	11
Duration of Care		
1 - 5 years	76	69.7
6 - 10 years	23	21.1
> 10 years	10	9.2

HIV: Human Immunodeficiency Virus; SCA- Sickle Cell Anaemia

3.4. Level of burden among the caregivers for the various domains

The level of caregivers' burden was low in all the domains studied, however, the area of disappointment (n=25; 22.9%) and general strain (n=21; 19.3%) had the highest levels of severe caregivers' burden (Table 4). The mean caregiving burden total score was 1.7 (SD=0.6). Mean score was highest in disappointment (2.0) and lowest in the domain of isolation (0.6).

Table 4 Distribution of level of burden among caregivers for the various domains.

Domains	Low n (%)	High n (%)	Total n (%)	Mean score	Std Deviation
Disappointment	84 (77.1)	25 (22.9)	109 (100.0)	2.0	0.7
General Strain	88 (80.7)	21 (19.3)	109 (100.0)	1.8	0.3
Emotional Involvement	98 (89.9)	11 (10.1)	109 (100.0)	1.6	0.5
Environment	98 (89.9)	11 (10.1)	109 (100.0)	1.6	0.7
Isolation	106 (97.2)	3 (2.8)	109 (100.0)	1.5	0.6

Overall mean score 1.7 Std Deviation 0.6

3.5. Distribution of Disappointment by demographic characteristics

More caregivers (n=25; 22.94%) were faced with disappointment as a burden in the care of their children compared to other domain of burden studied. Out of this, 12 (48.0%) were aged 30-39years, 15 (60.0%) were females while 13 (52.0%) had low monthly income. There was a statistically significant relationship between the burden of disappointment and age ($p = 0.007$), gender ($p = 0.003$) and income ($p = 0.037$) of the caregivers. Of the children of the caregivers, 18 (72.0%) were males, 19 (76.0%) had SCD, all (100%) had the diagnosis made at age 1-5years while 19 (76.0%) had received care for 1-5years. The burden of disappointment was statistically related to the age at diagnosis ($p = 0.002$) and duration of care ($p = 0.0001$) (Table 5).

Table 5 Distribution of Disappointment by Demographic information.

	Low N= (77.06%)	High n=25 (22.94%)	Chi-square (p-value)
Age Group			
20 - 29 years	4(4.76)	6(24.0)	
30 - 39 years	43(51.19)	12(48.0)	11.98 (0.007)*
40 - 49 years	23(27.38)	7(28.0)	
>50 years	14(16.67)	0(0)	
Gender			
Male	11(13.1)	10(40.0)	8.96 (0.003)*
Female	73(86.9)	15(60.0)	
Marital status			
Single	4(4.76)	0(0)	
Married	72(85.71)	25(100)	4.01 (0.260)
Separated	4(4.76)	0(0)	
Widowed	4(4.76)	0(0)	
Income (Naira**)			
<30000	21(25)	13(52.0)	
31000 - 150000	44(52.38)	8(32.0)	6.58 (0.037)*
151000 - 300000	19(22.62)	4(16.0)	
Child gender			
Male	52(61.9)	18(72.0)	0.85 (0.355)

Female	32(38.1)	7(28.0)	
Child diagnosis			
Cancer	8(9.52)	0(0)	
HIV disease	29(34.52)	6(24.0)	6.32 (0.097)
SCA	43(51.19)	19(76.0)	
Seizures	4(4.76)	0(0)	
Age at diagnosis			
1 - 5 years	53(63.1)	25(100)	
6 - 10 years	19(22.62)	0(0)	12.89 (0.002)*
> 10 years	12(14.29)	0(0)	
Years of Care			
1 - 5 years	57(67.86)	19(76.0)	
6 - 10 years	23(27.38)	0(0)	14.80 (0.0001)*
> 10 years	4(4.76)	6(24.0)	

*statistically significant (p<0.05); **one dollar = 450naira; SCA- Sickle cell Anaemia

3.6. Distribution of General strain by demographic characteristics

Table 6 shows the relationship between the caregiver’s burden of general strain and the socio demographic variables of the caregivers and the children. Twenty-one (19.27%) of the caregivers had a high score (severe burden) in general strain, among which 14 (66.67%) were aged 30-39years; 18 (85.71%) were females, 21 (100%) were married, 11 (52.38%) had a monthly average income of 31,000–150,000 naira. Also, among the children whose caregivers experienced the general strain burden, 15 (71.43%) and 6 (28.57%) had SCD and HIV disease respectively, all (100%) of them were aged 0-5 years at diagnosis while 12 (57.14%) had received care for 1-5 years. There was only a statistically significant relationship between severe burden of general strains and the age at diagnosis (p = 0.006).

Table 6 Distribution of General strain by Demographic information.

	Low n=88 (80.73%)	High n=21 (19.27%)	Chi-square (p-value)
Age Group			
20 - 29 years	10(11.36)	0(0)	
30 - 39 years	41(46.59)	14(66.67)	7.40 (0.06)
40 - 49 years	23(26.14)	7(33.33)	
>50 years	14(15.91)	0(0)	
Gender			
Male	18(20.45)	3(14.29)	0.41 (0.756)
Female	70(79.55)	18(85.71)	
Marital status			
Single	4(4.55)	0(0)	
Married	76(86.36)	21(100)	3.21 (0.359)
Separated	4(4.55)	0(0)	
Widowed	4(4.55)	0(0)	

Income (Naira**)			
<30000	28(31.82)	6(28.57)	
31000 - 150000	41(46.59)	11(52.38)	0.23 (0.892)
151000 - 300000	19(21.59)	4(19.05)	
Child gender			
Male	56(63.64)	14(66.67)	0.068 (1.000)
Female	32(36.36)	7(33.33)	
Child diagnosis			
Cancer	8(9.09)	0(0)	
HIV disease	29(32.95)	6(28.57)	3.93 (0.269)
SCA	47(53.41)	15(71.43)	
Seizures	4(4.55)	0(0)	
Age at diagnosis			
1 - 5 years	57(64.77)	21(100)	
6 - 10 years	19(21.59)	0(0)	10.33 (0.006)*
> 10 years	12(13.64)	0(0)	
Years of Care			
1 - 5 years	64(72.73)	12(57.14)	
6 - 10 years	17(19.32)	6(28.57)	2.01 (0.364)
> 10 years	7(7.95)	3(14.29)	

*statistically significant ($p < 0.05$); **one dollar = 450naira; RVD – Retroviral Disease; SCA- Sickle cell Anaemia

4. Discussion

In this study, more caregivers experienced severe burden in disappointment domain, followed by the general strain domain while isolation domain had the least level. The overall mean burden score experienced by caregivers in this study, which was 1.7, is low but comparable to findings from other studies where the obtained means of caregiving burden using this scale, varied between 1.98 and 2.1 [9,17,18]. The fact that majority (>90%) of the children in this study were stable outpatients on follow up may explain the low level of burden among caregivers in this study as many related studies were among hospitalized patients. Caregivers spend a large amount of time during inpatient care, and this may influence the level of burnout and burden experienced by caregivers.

More caregivers in this study felt disappointed and the reason for this may range from lack or failure of family members to meet expected needs, to failure of social and Government support. In this part of the world, families still enjoy a high degree of communal living which provides a good family and social support system. However, with chronic diseases requiring prolonged care, this support may wane gradually leaving the entire caregiving to mothers and/or very close relatives, which is usually a source of disappointment as was found in this study. Except for children with HIV disease who receive free anti-retroviral drugs, caregivers in this study did not benefit from government support of any kind and out of pocket expenditures on chronic diseases will significantly affect the burden of these caregivers since most had low earning capacity.

There was a statistically significant relationship between the gender of the caregivers, their age, income and the burden of disappointment. Majority of these caregivers who felt disappointed were younger (<40years), females (mostly mothers), and had low monthly earning ability (<30,000 naira). Low earning capacity of the caregivers as observed in this study was shown by Camargos et al [19] in a study among caregivers of children with cerebral palsy in Northeast Brazil, to have a negative and significant effect on the burden experienced by caregivers. In his study among children with cerebral palsy, Ortiz [20] found that mothers of children with chronic diseases accept higher responsibilities than other members of the family and usually play the caregiver role, and experience higher caregiving burden than males

as was found in this study. However, other studies found no difference in the burden of care based on gender [21,22]. One possible interpretation of this fact is that although it is more common for women to look after a sick child, by assuming this role, both parents are presented with similar experiences and challenges, and the different adaptive results are related to psychosocial aspects more than to demographic features per se [21].

In this study, there was a positive correlation between the caregivers' burden of disappointment and diagnosis in the first 5 years and the duration of care. Caregivers of children whose diagnosis was made early and who have been catered for more than 10 years felt more disappointed and this has been found in other studies [17,18,19]. This finding is expected, as logically the knowledge of a child's diagnosis at an early age and providing prolonged care for that child will adversely impact on the caregiver especially where the family and social support system has dwindled and/or is weak.

General strain was the next domain of burden experienced by caregivers in this study. General strain covers physical and emotional disturbances induced by caregiving activities, caregiving problems and required time for providing caregiving services. Though second to top in our study, Pegah et al. [9] and Kobos et al. [17] reported the highest caregiving burden in general strain and disappointment similar to the finding in this study, which found a significant relationship between general strain and diagnosis of chronic disease in the first five years of life. This relationship is also true here as it is in many domain of burden where early diagnosis of the chronic illness in the child will adversely place a high burden on some caregivers.

Surprisingly, this study found that in the domains of emotional involvement, environment and isolation, few caregivers experienced severe burden of care. This finding contrasts the observation of Rubira et al. [18], who identified isolation as the area with greatest burden. The fact that over 90% of caregivers in this study have secondary and post-secondary education may explain this low level of severe burden experienced in these domains. While being educated is not a proof to the burden of caregiving, some studies have shown that better educated people are more self-confident in dealing with various life situations, have better ability to cope with problems and have access to social support which can consequently alleviate their perceived burden [23-28].

Burden of caregiving was generally low or non-existent with the very young (<30years) and the older (>50years) caregivers. It is possible that the younger caregivers received better support from their families as is the practice in this area where grandmothers and other family members show support to young mothers in the care of their children while the older mothers/caregivers have grown to adjust to the disease condition and so are less burdened by it. Ge et al. [27], however found that younger caregivers were significantly associated with high caregiver burden. More married people experienced higher burden in this study and this may probably be due to the additional need to also provide care for other members of the family as many caregivers were female (Mothers). The fact that majority of these caregivers had low monthly income will heighten their burden knowing that these chronic illnesses place a huge demand on the meagre family income.

5. Conclusion

In conclusion, this study found a low level of burden among caregivers of children with chronic diseases. High levels of burden were more experienced by caregivers in the domains of disappointment and general strain while the isolation domain experienced the least level. Also, these areas of burden suffered by caregivers had a positive significant correlation with the gender, age, sex and family income of the caregivers and the age at diagnosis, and duration of care.

The authors recommend a patient-centered care with the focus on improving social support. Also, the Paediatric Association of Nigeria should advocate that Government should take over the financing of medical expenses of children with chronic diseases especially those older than five years as this will ameliorate the burden of care experienced by their caregivers.

Compliance with ethical standards

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Disclosure of conflict of interest

The authors declare no conflict of interests.

Statement of informed consent

Informed consent was obtained from all caregivers/parents who participated in the study.

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