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A Mixed Method Study of Burden of Care and Its Associated Factors Among Informal Caregivers of Individuals with Spinal Cord Injury in Nigeria

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ABSTRACT

Background: Information about the burden of care and factors associated with it among caregivers of individuals with spinal cord injury is fundamental in planning programs to alleviate their burden.

Methods: We conducted the study using a mixed-method design of the cross-sectional survey and qualitative study. Thirty-four participants (informal caregivers of individuals with spinal cord injury) for the study were purposively selected at the foremost tertiary hospital in Nigeria. The Zarit Burden Interview (ZBI) questionnaire was used to assess the level of burden of care. In addition, seven purposively selected informal caregivers also participated in the focus group discussion. Descriptive and inferential statistics were used to analyze the quantitative study, while the qualitative data were analyzed using thematic content analysis.

Results: Findings of the cross-sectional study showed that 28 (82.4%) participants had a high level of burden of care. Significant associations were found between the burden of care and the level of income of participants ($p=0.042$), the burden of care, and the number of hours spent caring ($p=0.005$). The qualitative study revealed poor hospital administration and logistics, high cost of care, and negative attitude of health workers as what constitute the burden.

Conclusion: The informal caregivers experience a high level of burden of care, associated with poor hospital administration, health workers attitude, and high cost of care.

Keywords: Informal caregivers, the burden of care, Spinal Cord Injury, Mixed Method Design, Health workers.

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INTRODUCTION

Spinal cord injuries (SCI) have long-term consequences on body parts, including paralysis, bladder, bowel and sexual dysfunctions, autonomic dysfunction, pain, and other sensory dysfunctions [1,2]. Globally, the estimated rate of SCI varies between 40 and 80 million cases per population, while the annual incidence of SCI is between 250,000 and 500,000 [3]. In developed countries, the annual incidence per million people is 13.1 to 163.4 per million people [4], while in developing countries, the annual incidence of spinal cord injuries ranges from 2.1 to 130.7 per million people per year, with males comprising 82.8% and a mean age of 32.4 years [5]. In Nigeria, the actual annual incidence of spinal cord injury is unknown because of the lack of consistency in reported data [6]. Individuals with spinal cord injury undergo rehabilitation, which aims to diminish symptoms, increase independence, return to regular activities and enhance the quality of life [7].

Rehabilitation of individuals with spinal cord injury is associated with a significant burden on the caregivers [8]. The burden of care is a multidimensional response to the negative appraisal and perceived stress resulting from taking care of a patient. This multidimensional response of the burden of care encompasses four areas: the structure of care, the stressful process of caregiving, factors that lessen the perception of stress, and the aftereffect of caregiving on the general wellbeing of the caregiver. The care structure includes the caregiver's characteristics, the relationship between the patient and the caregiver, and available social support. The stressful process of caregiving may be patient-centered, i.e., the behavior of the patient or caregiver-centered, i.e., other commitments of the caregiver. Factors that abate the perception of stress include the coping strategies and management principles of care [9]. The burden of care can be divided into an objective and a subjective component [10]. The objective component has to do with the external or quantifiable aspect of caregiving, such as the cost of treatment and the time it takes to provide care for the patient. At the same time, the subjective component has to do with the psychological consequences or strain reported by caregivers when performing their role [11].

An informal caregiver is saddled with providing care for one with any form of activity limitation and participation restriction [12]. Usually, such cares include support and guidance and are associated with a significant burden [13]. Studies have shown that factors affecting care burden on informal caregivers vary in different climes and culture plays a role in influencing one's behavior, fortitude, and the estimation of one's burden of care [14]. It is important to note that most of the research on the burden of care on informal caregivers of individuals with spinal cord injury is mainly from developed countries [15]. In contrast, developing countries like Nigeria, with the increasing prevalence of spinal cord injury, have little or no data on the burden of care among informal caregivers of patients with spinal cord injury [5,16]. Availability of information

on the burden of care and factors associated with it among caregivers of individuals with spinal cord injury is pivotal for planning any programs for the caregivers [17]. Hence, this study explores what constitutes the burden of care, the level of burden, and factors associated with the burden of care among informal caregivers of individuals with spinal cord injury in Nigeria, a developing country.

MATERIALS AND METHODS

We obtained ethical approval for the study from the University of Ibadan/University College Hospital Health Research Ethics Committee (UI/EC/19/0450) before the study was commenced. This study was a mixed-method study (Cross-sectional study and explorative qualitative design using focus group discussion). The participants were consenting informal caregivers of individuals with spinal cord injury who attended the Physiotherapy outpatient clinic and Neurosurgery ward of a tertiary hospital in Nigeria. The Inclusion criteria were that the participants were the primary informal caregivers, have been performing caregiving roles for at least four weeks, and are adults aged 18 years and over. In addition, informal caregivers whose relatives had other neurological conditions were excluded from the study.

Data were collected quantitatively using a socio-demographic questionnaire and The Zarit Burden Interview (ZBI) questionnaire, hand-distributed, self-administered, or administered by interview. Data were analyzed using descriptive statistics of mean, frequency, standard deviation, and inferential statistics of Chi-square, Mann-Whitney U tests, and Cramer's V tests. The qualitative data were collected using a focus guide and audio recorder. The developed focus guide was used to guide the discussion with randomly selected seven informal caregivers, which lasted about one hour. One of the authors (NO), experienced and has publications in qualitative research, moderated the focus group discussion. The discussants were allowed to discuss freely what constitutes their burden of care. While the discussion was being recorded, an independent observer also took notes. The moderator asked other questions and used probes when necessary to stimulate the discussion. The recorded information from the discussion was transcribed verbatim by a transcriptionist. Content, thematic analysis was used to analyze the data. Emerged categories and themes were identified. Data check and validity was done by comparing the recorded conversation with the note taken.

RESULTS

Socio-demographic Characteristics of Participants (Informal Caregivers)

Thirty-four informal caregivers of spinal cord injured individuals with a mean age of 41.26 ± 11.39 years participated in this study. They comprised 22 (64.7%) females and 12 (35.37%) males. 15 (44.1%) participants were spouses of the spinal cord injured individuals, 9 (26.5%) were relatives of the spinal cord injured individuals, 5 (14.7%) were children of the spinal cord injured

individuals, 4 (11.8%) participants were the parents of the spinal cord injured individuals, and 1 (2.9%) participant was a friend of the spinal cord injured individual. 19 (55.9%) participants had a tertiary education, 9 (26.5%) participants had a secondary school education, 3 (8.8%) participants had a primary school education, while 3 (8.8%) participants had no formal education. (Table 1)

Table 1: Socio-demographic Characteristics of Participants (N = 34)

Variables	Frequency(n)	Percentage (%)
Age (years)		
20-29	5	14.7
30-39	12	35.3
40-49	6	17.6
50-59	10	29.4
60 and above	1	2.9
Mean age (±SD)	41.26 (±11.39)	
Gender		
Male	12	35.3
Female	22	64.7
Marital status		
Married	27	79.4
Unmarried	7	20.6
Educational Level		
Tertiary	19	55.9
Secondary	9	26.5
Primary	3	8.8
No formal education	3	8.8
Level of income		
High	4	11.8
Middle	27	79.4
Low	3	8.8
Relationship with patient		
Spouse	15	44.1
Extended relative	9	26.5
Child	5	14.7
Parent	4	11.8
Friend	1	2.9

Classified Level of Burden among Participants

Participants with a ZBI ≤ 20 were classified as a low burden, while participants with a ZBI ≥ 21 is classified as a high burden. Six participants (17.6%) had a low level of burden, while 28 participants (82.4%) had a high level of burden. The median (IQ) burden score of the participants was 34.5 (22.75) (Table 2).

Table 2: Distribution of participants' level of burden

Variables	Frequency (n)	Percentage (%)
Burden Level		
Low (ZBI score ≤ 20)	6	17.6
High (ZBI score ≥ 21)	28	82.4
Median (IQR)	First Quartile	Second Quartile
34.5 (22.75)	23.50	46.25

Participant's responses to the burden of care

Eleven participants (32.4%) felt that their relatives requested help quite frequently, 10 (29.4%) sometimes. On the other hand, 16 (47.1%) participants had no time for themselves because of their time caring for their relatives, and 7 (20.6%) participants sometimes felt they had no time for themselves. Six (17.6%) participants felt their relatives were dependent on them; eight (23.5%) participants felt their relative was dependent on them quite frequently, nine (26.5%) participants sometimes felt their relative was dependent on them. In comparison, ten (29.4%) participants felt their relative was not dependent on them. Five (14.7) participants felt their health has suffered because of providing care for their relatives, seven (20.6%) participants rarely felt their health has suffered because of involvement with relatives. In comparison, ten (29.4%) participants never had any health issues because of patient care involvement (Table 3).

Table 3: Distribution of selected key participant's responses to burden of care (N = 32)

Questions	Never	Rarely	Some Times	Quite Fre- quently	Nearly Always
	n (%)	n (%)	n (%)	n (%)	n (%)
Do you feel that your relatives ask for more help than he/she needs?	5 (14.7)	4 (11.8)	10 (29.4)	11 (32.4)	4(11.8)
Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	3 (8.8)	4 (11.8)	7 (20.6)	4 (11.8)	16 (47.1)
Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	7 (20.6)	4 (11.8)	10 (29.4)	6 (17.6)	7 (20.6)
Do you feel embarrassed over your relative's behaviour?	27 (79.4)	4 (11.8)	-	2 (5.9)	1 (2.9)
Do you feel your relative is dependent on you?	10 (29.4)	1 (2.9)	9 (26.5)	8 (23.5)	6 (17.6)
Do you feel your health has suffered because of your involvement with your relative?	10 (29.4)	7 (20.6)	8 (23.5)	4 (11.8)	5 (14.7)
Do you feel that your social life has suffered because you are caring for your relative	11 (32.4)	4 (11.8)	2 (5.9)	12 (35.3)	5 (14.7)
Do you feel uncomfortable about having friends over because of your relative?	26 (76.5)	4 (11.8)	2 (5.9)	1 (2.9)	1 (2.9)

Do you feel that you don't have enough money to care of your relative in addition to the rest of your expenses?	11 (32.4)	-	8 (23.5)	7 (20.6)	8 (23.5)
Do you feel you have lost control of your life since your relative's illness?	13 (38.2)	6 (17.6)	5 (14.7)	8 (23.5)	2 (5.9)
Do you wish you could leave the care of your relative to someone else?	21 (61.8)	3 (8.8)	9 (26.5)	1 (2.9)	-
Overall, how burdened do you feel in caring for your relative?	6 (17.6)	4 (11.8)	10 (29.4)	9 (26.5)	5 (14.7)

Level of Burden between male and female

Out of the 12 male participants, three (25%) had a low level of burden of care, nine (75%) had a high level of burden of care. Out of the 22 female participants, three (13.6%) had a low level of burden of care, and 19 (86.4%) had a high level of burden (Figure 2). There was no significant difference in the level of burden of care between male and female participants (Table 4).

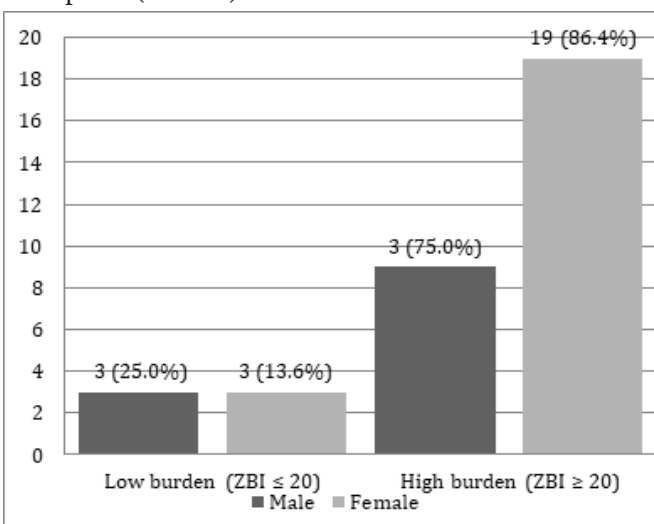


Figure 1: Distribution of participant's level of burden between the male and female using proportion

Table 4: Difference in the Burden of Care between Male and Female participants using Mann-Whitney U test

Mann-Whitney U test			
Mean Rank	Male	Female	16.25
			18.18
Value			117.00
P-value			0.413

The burden of care and age of participants:

The age group between 20 and 29 years consists of five participants. Two (40.0%) of the participants had a low level of burden of care, while three (60.0%) participants in the same category had a high level of burden of care. Participants in the age category of 30 to 39 had two (16.7%) participants with a low level of burden of care and 10 (83.3%) participants with a high level of burden of care. The age category of participants between 40 and 49 showed one

(16.7%) participant with a low level of burden of care and five (83.3%) participants with a high level of burden of care. Participants in the age category between 50 and 59 had one (16.7%) participant with a low level of burden of care and 5 participants (83.3%) with a high level of burden of care. Only one (100%) participant was in the age category of 60 and above and had a high level of burden of care (Figure 1). However, there was no significant association between age and burden of care (Table 5).

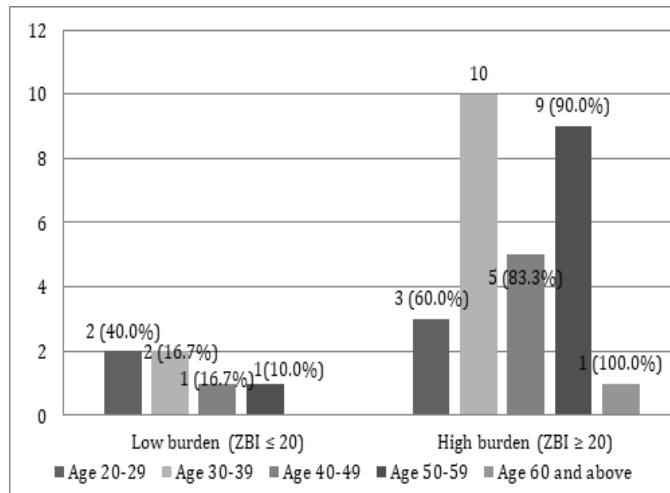


Figure 2: Distribution of age and burden of care using proportion.

Educational level and burden of care

There were 19 participants with tertiary education, of which three (15.8%) had a low level of burden, while 16 (84.2%) participants with tertiary education had a high level of burden. Out of the nine participants with secondary education, three (33.3%) had a low level of burden, while six (66.7%) had a high level of burden. All three participants (100%) with no formal education had a high level of burden (Figure 3). There was no significant association between educational level and burden of care (Table 5).

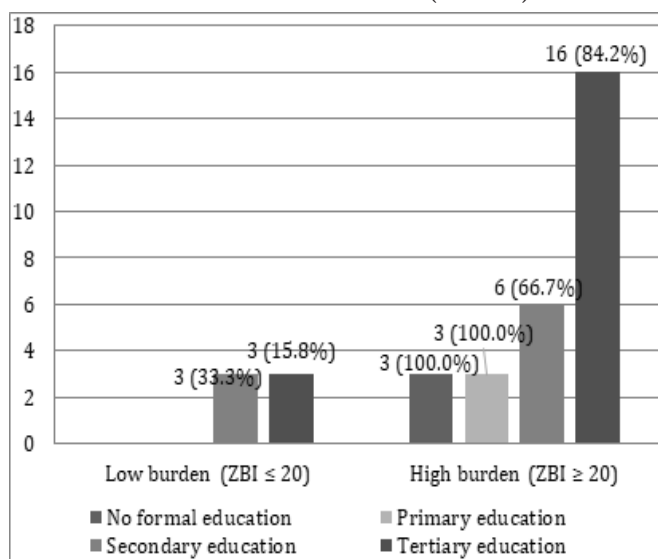


Figure 3: Distribution of Level of Education and Burden using Proportion

Level of Burden and Level of Income

Out of the four participants with a high level of income, 3 (75%) had a low level of burden. Three (11.1%) of the

participants with a middle income had a low level of burden, while 24 (88.9%) participants with a middle income had a high level of burden. Three (100%) participants with a low income had a high level of burden, while no participant with a low income had a low level of burden (Figure 4). Thus, there was a significant association between the level of burden and income level (Table 5).

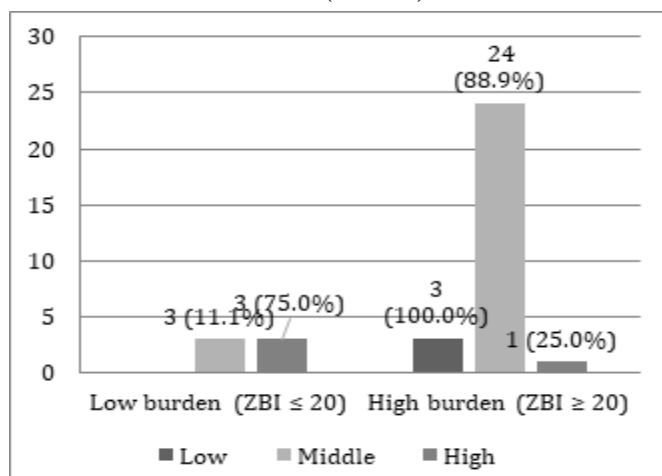


Figure 4: Distribution of participant's level of income and burden using proportion

Level of Burden and Number of Hours spent with Patient

Twenty participants (95.2%) with high burden spent ≥ 18 hours providing care for the patient, while one participant (4.8%) with a low level of burden spent ≥ 18 hours providing care for their relative. Six participants (60.0%) with a high level of burden spent ≤ 12 hours providing care for their relatives, while four participants (40.0%) with a low burden spent ≤ 12 hours providing care for their relatives. Two participants (66.7%) with a high level of burden spent ≤ 6 hours providing care for their relatives. In contrast, one (33.3%) participant with a low level of burden spent ≤ 6 hours providing care for their relative (Figure 5). A significant association was found between the level of burden and the number of hours spent providing care (Table 5).

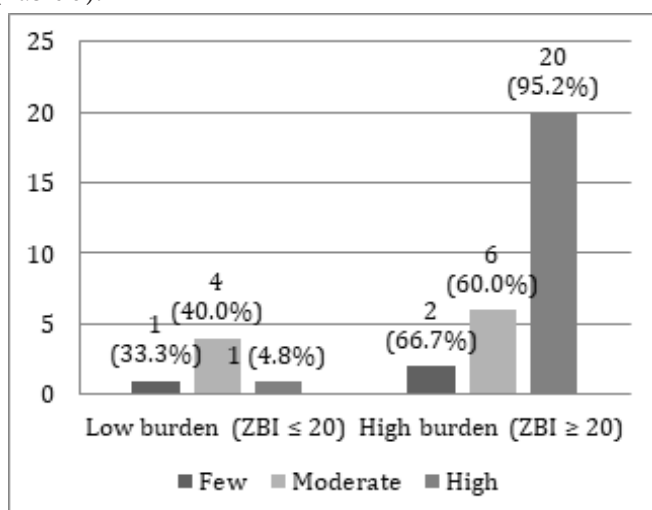


Figure 5: Distribution of Number of Hours spent with Patients and Burden using proportion

Table 5: Association between age, level of education, level of education, level of income, number of hours and level of burden using Chi-square and Cramer's V test

		Value	Approx. Sig.
Age	Likelihood	1.117	0.773
	Cramer's V	0.193	0.730
Level of education	Chi-square	2.855	0.301
	Likelihood Ratio	3.657	0.301
	Cramer's V	0.290	0.415
Level of income	Chi-square	10.490	0.005
	Likelihood Ratio	8.352	0.015
	Cramer's test	0.290	0.005
Number of hours	Chi-square	6.345	0.042
	Likelihood Ratio	6.368	0.041
	Cramer's V	0.432	0.042

Exploratory Qualitative Study of the Burden of Care among Informal Caregivers of Spinal Cord Injured Individuals in Ibadan

A qualitative study to further explore the burden of care among informal caregivers of spinal cord injured individuals in Nigeria using focus group discussion was conducted. During the discussion, knowledge of spinal cord injury, causes of spinal cord injury, the burden of caregiving during admission, challenges associated with caregiving such as financial difficulties, health challenges, the psychological and social burden of care, emotional health challenges, and sexual health were explored. Seven informal caregivers (4 males; 3 females) participated in the focus group discussion. For the discussion, participants were called by numbers assigned to them; 1, 2, 3, 4, 5, 6, 7, and their age, sex, level of education, and relationship with the patient are summarized in Table 6. In addition, participants were asked questions about the aim of the study. This article reports information received from participants concerning the level of burden and associated factors.

Knowledge of Spinal Cord Injury

The meaning of spinal cord injury

Spinal Cord Injury (SCI), as defined by most discussants, is an injury to the spinal cord caused by a road accident, a fall, or a degenerative disease such as tuberculosis. Discussants mentioned different ways one can sustain a spinal cord injury. They include a clash, a road accident, and an infection to the spinal cord. Some also said SCI starts as an imbalance movement that can later lead to total loss of movement. Some first thought of it as malaria and as back pain. The excerpts:

'My understanding of what happened to my relative is: I know it is a spinal injury. It was an accident.' (Participant 1)

'What I understand about the issue of my wife, it all started first as imbalance movement. That is how it started, so later we thought it was malaria; after that, little by little, it graduated to emm, she was not able to move again until we reach this place. The doctors discovered that it was likely to be TB, tuberculosis. The one at the spine said that it is called

extrapulmonary tuberculosis; so, the one that happened or affected my wife is extrapulmonary or spinal.' (Participant 4)
'She used to have back pain, so suddenly it started affecting the leg, so when that happened, I said, ah, what concerns back pain with a leg? And we thought of what would happen now, and we started receiving treatment.' (Participant 7)

The causes of spinal cord injury

Some respondents explained how their patients sustained SCI through a road accident and an infection after surgery. A discussant explained:

'The vehicle somersaulted. My wife said there was a serious pain in serious pain that emm, she needs somebody to help her out quickly...When we reach the hospital, we quickly took x-ray and they said, ah! They cannot do that, emm there is bulge...you know the medical explanation. They started looking at bulge...but they did the operation and after two weeks, infact, it could have been after a week she could have been standing emm, she could have been sitting down but she developed some infection along the operation.' (Participant 3)

The prognosis of spinal cord injury

Some respondents mentioned doctors explained the problem and prognosis, but they believed God would intervene despite the medical prognosis. Below are the excerpts;

'Yes, they told us and we said how everything happened.' (Participant 5) 'Emm, it is my husband that is on admission. He had an accident in July and when we got here, we were told that it has affected his spine that we will do surgery but later after spending 3 months, so they said we don't need surgery that God has taken control that he is getting well little and lifting his leg by little that we should commence physiotherapy. Then we were also told that he had fracture to both legs. With the help of God, God has taken control.' (Participant 5)

'We've spent up to 5 months. They said he will not be able to walk again, he will not be able to do one thing or the other. We will have to get wheelchair, I said no because I have faith in God. All I was told then even the surgery I said no he won't do surgery that I know God will do it that he will walk. God is taking control the result we have been seeing with the help of physiotherapy God has taken control.' (Participant 5)

The burden of caring for a patient while on admission and factors associated

Spinal cord injury is associated with a great burden on the patient and caregivers. The factors associated with discussants were physical exhaustion caused by non-functional lift for ease of movement, sleep deprivation, financial difficulties, and negative attitudes of health workers. Some of the responses of the discussants concerning the burden of care are classified as:

Physical exhaustion due to hospital administration logistics

Discussants mentioned the stress associated with walking the distance between hospital wards and places of

purchasing drugs and other needed things demanded for care. The non-functioning lifts, no place to sleep and no easy access as the causes of physical exhaustion:

'Buying things for the patient is one of the stress, you will go to A to pay money, go to B they will send you back to C, is a terrible journey. Then this staircase is another, you may be having your patient on the first floor, they will say you must go to the third floor to collect something, you will be running up and down, you know the staircase. In fact, that is one of the things, if they say this is neuro, I mean spinal problem. Let everything they can use for that spinal problem be along the line with the spinal ward. Okay you want, somebody is having problem at the back...I will push from that place even with bed from x-ray down you know, you that is pushing the person on the bed is not even enjoying yourself. I don't understand why it is like that. There must be an easy access.' (Participant 3)

'...Lifts are not working, even the ones that are working before you wheel the patient there it is not easy. That is one aspect, the second aspect is where to sleep, the challenges, okay, there is a time they will call me like 12am in the night that I should come and look at something, that night they tell me to go and pay for one test about 2or 3 tests that I paid for that night. Apart from that, you know how they pay here. First of all, you will go to where they are collecting money, go up this, and that it is stressful for my sister. It is not a thing somebody can register in his brain to continue.' (Participant 3)

Loss of money

'Is it the problem of payment challenges? A lot of my money enters their purse, no change; no change, I cannot get it out. Is it the doctor's prescription? Go and take that from...., you know when you are with patient you will want to do everything so that anything will not even remain for that patient so that the doctor will not be complaining to you that you didn't cooperate. I will go and pay but after payment, they will not, they don't want to use it again. I still have money to be refunded, in fact, I have left some. If I start running up and down, one will become a mad person. You see that is some of the challenges here. They are enormous.' (Participant 3)

Financial cost of care

'They said we would do MRI, #70, 000. The following morning, we were told that we have to do a scan of #40, 000. I thought about it that since it is the government's machine, it shouldn't be that expensive; shouldn't we be expecting them to use the money to run this big organization? If it was outside and it's worth #100,000, in a government hospital is meant to be #20/#30,000 because it is government that owns it. We have access that is the primary responsibility of the government to give us health care, it's our right.' (Participant 7)

'One certain time we were asked to go for x-ray no x-ray. We came to this ehmm the department to ask. They said the only x-ray they can do is that if only the person can sit on a wheelchair and you know you've a lot of patient that can't sit nor stand, so why would you machines not be available?

Okay, we agreed taking the patient outside, you asked us to go and pay for ambulance. They collected money for ambulance and we were asked to pay money for the fuel, fuel fee or so that the ambulance money separately, money for the fuel is a separate one. Why are we paying for the fuel and we are still paying for the ambulance, are they not the same thing and the nurse that is supposed to go there with us we are asked to pay for the nurse again for? But is their work, they know what they are supposed to be paying, they pay them their salary, we are not supposed to pay such money again. Then the charges are too much, it is true' (Participant 1)

Negative attitudes of health workers

'I know they believe that nurse will take care of everything that is why they say, emm, go away o, leave the patient for us, but when you leave the patient for them that is another story. If I'm to be saying another person's emm situation now you will be saying that's not my own case because...that case affected me, I was called by a nurse at 12am to come and take care of my wife on the ward, another man on the ward was calling me that I should come and help him remove his pampers that he has defaecated on the pampers o that I should come. I said emm, I went to that nurse, please nurse help this man, he has already defaecated on the diapers, she said that emm, the wife went and slept somewhere, she wants him to be packing shit. Look at that, but you are the one who asked us (the relatives) to go.' (Participant 3)

'...You are the one that asked us to even leave. Let me be sincere, as you see me as a man, I was, I'm the one I mean that clean up my wife when she defecates in the ward. I'm the one that is cleaning it because I don't want to wait for nurses. When you call, nobody will respond, these are part of the challenges and you know they will be saying that ehmm, the toilet here is for the patient, the patient. The spinal injury patient, can he use the toilet? You don't want the person that is sitting by the side helping you in the work to, the person that is helping you cannot use toilet. They will lock the toilet. You know all these things are uncalled for. As you see me now, I'm a young man o

but you can't imagine what kind of house I could have been using at home. What kind of toilet I could have in my own house? But even here that I'm even afraid of sitting in the toilet somebody will not allow me to urinate.' (Participant 3)

'Then the doctors do something they don't communicate with the patient. It is during their discussion; you can have an idea of what they are saying. You won't know the patient's position. If they have given her treatment, you may not know. Your complaint if they have addressed it, you may not know. They will just be discussing among themselves. It's just because somebody is educated that's why you can get what they are discussing. They won't say madam by tomorrow you should be able to walk, that is what we've done. They will not talk to you and here, honestly is not for the masses. It is for the rich and the elite.' (Participant 7)

'When we are in the hospital, in fact, there are some among the health workers that are good, that even when one is going home after discharge, one should get their contact, these

people are human beings and one should relate with them the way they are treating someone. But some are uncaring, nonchalant, and lackadaisical towards fellow human beings. In short, one mama (an elderly woman) releases something that stinks and she was brought close to my wife who is a young lady and to sleep is even...and for her to be seeing that mama close to her. I went to meet the nurse that there is another space why not allocate it to us. So simple, if you see the way she shunned us. My daddy came, he is an elderly person, he also retired at this institution. He spoke to the nurse; she acted as if nobody was talking to her. She thought I was the only one on ground. Meanwhile the nurse did not know that we know people. We didn't want to do...so that it won't be that we are reporting somebody.' (Participant 7)

Let's not talk only about the negative aspects; the hospital is up to the task honestly. They have academically solid professionals, intellectually, capable and they know, they are experts. In short, it gives one rest of mind. But their attitude, maybe the hospital is short staffed or some of the staff are not rewarded. You will see that some are not happy while working." (Participant 7)

Sleep deprivation caused by no place for caregivers to sleep

'They call a place Alanu's house, we were asked to pay #500 per night. They call somewhere Alanu's house...you know the accommodation; the rooms there are not many. They have only 6 rooms for the female and 6 rooms for the male and you know how big the hospital is and you still insist that you need only one person in a room...Some people have been on the bed for like months, you understand and they have been in one particular room, there is no other place you can go. Why is it like that and there is no provision for where the relatives can stay?' (Participant 1)

"I pity those coming outside this city of Ibadan very well. Those coming from far place at least I stay around, sometime I can go home to have my bath and comeback." (Participant 7)

'Since I got here, it's been 20 days have not had sound sleep from night to morning. I sleep inside my car and the mosquitoes here, if they bite a white man he will die. The first time I could not sleep for 5 days, I could not sleep and I walked from morning until night and I didn't sleep at all...so the way I'm, my health has been really affected.' (Participant 7)

Table 6: Socio-demographic characteristics of focus group discussion

Participants Number	Age	Sex	Relationship with patient	Educational level
1	30	Female	Sister	Tertiary
2	49	Female	Mother	Tertiary
3	57	Male	Husband	Tertiary
4	52	Male	Husband	Tertiary
5	45	Female	Husband	Secondary
6	22	Male	Sibling	Secondary
7	36	Male	Spouse	Tertiary

Table 7: Themes and sub-themes of focus group discussion

Themes	Sub-Themes
Understanding of spinal cord injury	The meaning of spinal cord injury
	The causes of spinal cord injury
	The prognosis of spinal cord injury
The burden of caring for patient while on admission and associated factors	The burden is high due to: Physical exhaustion from hospital administration & logistics. Walking long distances within hospitals and climbing staircase several times without elevators
	Loss of money
	High cost of care
	Negative attitude of health workers
	Sleep deprivation caused by no places for caregivers to sleep

DISCUSSION

Socio-demographic characteristics of informal caregivers, the burden of care, and factors associated with a high burden of care

Participants of this study were primarily females and wives of the injured patient who provided care for at least one month. This finding is similar to previous studies where most informal caregivers were females being wives or sisters of persons with paraplegia (Blanes et al., 2007). However, a study conducted among informal caregivers of spinal cord injured individuals in Iran revealed that the majority of the informal caregivers were males and were extended relatives of the injured individuals [11]. The possible reason for the findings in this study may be because the spinal cord injury of traumatic cause constitutes the highest type of spinal cord injury, and in African culture, males are the breadwinners of the family and are more involved in activities that predispose them to traumatic injury [18]; therefore women are left to care for them.

The burden of care was high among the majority of this study participant who was middle-income earners. A high burden of care was associated with the income level, and most middle-income earners had a high burden of care. This may be because most middle-income earners in the informal sector in Nigeria have no health insurance coverage and have to pay out of pocket, resulting in financial difficulties [19]. In addition, the cost of paying for hospital bills and the stressful process involved in recovering money not utilized inpatient care could increase the burden. The qualitative study further buttressed these points and highlighted other associated factors such as physical exhaustion, negative attitude of health workers, lack of communication between the physician and informal caregivers about the patient's condition. The poor structural organization and hospital logistics, particularly the poor facility planning and operational protocols of the Nigerian hospitals [20], could be associated with physical exhaustion. The caregivers may walk some distance and experience some unnecessary delay while trying to get

the hospital patient's needs met. More so, the negative attitude of the health care provider could be perceived to be an adverse response to the frustrating situation of the healthcare system in Nigeria, as the healthcare providers are only not well remunerated, the workload is high patients to healthcare providers ratio is disproportionate [20–22]. However, we do not excuse the negative attitude of health workers in Nigeria in this case. We are only trying to look at this factor objectively, bearing in mind other challenges of the Nigerian health system. Health workers are expected to have the right attitude toward their work and their patients. The factors mentioned above are context-specific problems and may be found in some developing countries like Nigeria. Therefore, there is a need to train and encourage health workers to have the right attitude and, more importantly, improve the health system.

Many informal caregivers did not accept the prognosis of spinal cord injury given by physicians because of religious beliefs. We opine that this type of attitude of informal caregivers could lead to denial of the problem and hoping on what may not be realistic, resulting in frustration and depression after a long while. Culturally, people living with disabilities are seen as outcasts, excluded from normal life, and people feel once they have a disability, they are not normal human beings; as such, they want to reject this possibility and hope for a miracle. We opine that proper communication between the informal caregivers and health care professionals, particularly doctors and physiotherapists, will help informal caregivers to accept the prognosis and adjust adequately to the demands of care for spinal cord injured patients.

This study showed no significant association between the age of participants and the burden of care. This finding is similar to a study by [23]. A possible explanation for this is that both young and old informal caregivers are faced with similar challenges in caring for their relatives. Furthermore, no significant association was observed between the level of education and burden. This might be because most participants had tertiary education and could better cope with the stressful process of caregiving.

The result from this study showed that there was no significant difference between the burden of care between male and female participants. This result is similar to a previous study where no significant association was found between the burden of care and gender (24). However, a significant association was found between the hours spent providing care for patients and the burden of care. This finding is similar to the result from a previous study by Blanes et al. in 2007. The majority of the participants had a high level of burden of care. This finding is similar to a previous study carried out in China to investigate care burden and coping style in caregivers of spinal cord injury. Most caregivers had a moderate to severe burden (16). However, this study did not classify the level of burden as moderate or severe. So, it is possible some who fell into high burden could have been intermediate. The majority

of the informal caregivers were not embarrassed over their relative's behavior; this is because, in African culture, people are expected to take care of their family members regardless of their misfortunes. It is believed to be an act of irresponsibility and lack of genuine love if one hand over the care of a family member to someone else [25].

African culture has its advantages and disadvantages in the care of spinal cord injured patients. The culture helps the patients to get family support and the informal caregiver to accept responsibility sacrificially. However, handling the burden of care needs more than the culture; education, finance, hospital policies, protocols, and staff attitude affects how

the burden is borne, there is a need to strengthen the health system and develop programs for informal caregivers to sustain caregiving for spinal cord injured patients, which may be a life-long job for the informal caregivers or at least till the miracle they hope for comes as it is a possibility in the spiritual context of care which is evolving in science.

CONCLUSION

The government, hospital managers, and health care providers should facilitate the enactment of policies that will substantially relieve the burden of care on the informal caregivers. A majority of the informal caregivers experience a high level of care burden, associated with poor hospital administration, health workers attitude, and high cost of care.

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