

Association Between Quality of Life and Burden of Care Among Informal Caregivers of Individuals with Spinal Cord Injury: A Mixed Method Study

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Citation: Odunaiya NA, Omosehin R, Ojo JO. Association Between Quality of Life and Burden of Care Among Informal Caregivers of Individuals with Spinal Cord Injury: A Mixed Method Study. *Neurol Res Surg.* 2021; 4(1): 1-7.

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Received: 09 July 2021; **Accepted:** 15 August 2021

ABSTRACT

Purpose: Informal caregivers of individuals with spinal cord injury often experience high burden of care which could impact negatively on quality of life. Exploring the impact of the burden of care on the quality of life is required in developing necessary health promotion programs for informal caregivers.

Method: The study utilized a mixed method design of cross-sectional survey and qualitative study. The cross-sectional component involved purposively selected 34 consenting informal caregivers of individuals with spinal cord injury from the physiotherapy outpatient clinic and neurosurgery ward of a major tertiary hospital in Nigeria. The Zarit Burden Interview (ZBI) questionnaire was used to assess the level of burden of care and 36-short form health survey questionnaire. Seven purposively selected and consenting informal caregivers participated in the focus group discussion. Mann-Whitney test and spearman correlation were used to analyze the quantitative study. The level of significance was set at 0.05. The qualitative data was analyzed using content thematic analysis.

Results: The mean age of participants in this study was 41.26 ± 11.39 years. The cross-sectional study showed that 28 (82.4%) participants had a high level of burden of care. Out of all the domains of quality of life, vitality and mental health had a significant relationship with burden of care. The qualitative study provided further insight into the study. According to the participants, psychological, emotional, social and sexual functioning were affected negatively by the burden of care of individuals with spinal cord injury.

Conclusion: Quality of life of informal caregivers is negatively affected by high burden of care experienced.

Keywords

Quality of life, Burden of care, Informal caregivers, Spinal cord injury.

Introduction

Spinal cord injury (SCI) is a devastating, life-altering injury. It is a challenge for clinicians and informal caregivers to manage because of the long-term consequences on the body parts, which include paralysis, bladder, bowel and sexual dysfunctions, autonomic

dysfunction, pain and other sensory dysfunctions [1-2].

Many persons with spinal cord injuries face challenges regarding their physical, psychological and social functioning, and a substantial proportion of individuals with spinal cord injury need support in these areas for the rest of their lives [3-4]. Spinal cord injury does not only markedly affect the patients' functioning but also place high demands on their informal caregivers [5] who are usually close relative of these patients. It is worth noting that in

developing countries, the international communities advances have not impacted on the majority of individuals with spinal cord injury, as such the burden of care is usually borne by the informal caregivers [6] This burden could largely affect the quality of life of informal caregivers of individuals with spinal cord injury [7].

The World Health Organization (WHO) defines quality of life as individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment [8] Studies in developed countries have shown that informal caregivers of individual with spinal cord injury experience poor quality of life compared with people in general population who are not caregivers [9-11]. Various domains of quality of life (mental health component [12] and physical health component [9] of informal caregivers were negatively affected.

Increasing occurrence of spinal cord injury in developing countries like Nigeria [13] implies increased burden of care for informal care givers. Unfortunately, quality of life of informal care giver is given little attention in literature in developing countries. Since most individuals with spinal cord injury will need support of informal caregivers throughout their lives, the quality of life of informal caregivers is important in fulfilling this obligation. Therefore, the need to know the association between the burden of care and quality of life of informal caregivers. This study aimed to determine the association between the burden of care and quality of life of informal caregivers of individuals with spinal cord injury in Nigeria. The findings of this study may help develop interventions to improve the quality of life of informal caregivers and consequently influence the care provided to individuals with spinal cord injury positively.

Materials and Methods

Ethical approval for the study was sought and obtained from the University of Ibadan/University College Hospital Health Research Ethics Committee (UI/EC/19/0450) before the commencement of the study. A mixed method design consisting of a cross-sectional study and exploratory qualitative study (Focus Group Discussion) was utilized. The participants in this study were purposively selected from Physiotherapy outpatient clinic and Neurosurgery ward of the largest tertiary hospital in Nigeria where most individuals with spinal cord injury are referred to for care. The Inclusion criteria were that the participants were the primary informal caregivers, have been performing caregiving role for at least 4 weeks and are adults aged 18 years and over. Informal caregivers who's relative had other neurological conditions were excluded from the study.

Data were collected quantitatively using, socio-demographic questionnaire and The Zarit Burden Interview (ZBI) questionnaire and 36-short form health survey questionnaire, which were hand-distributed, self-administered or administered by interview. Data were analysed 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 was collected using focus group discussion. Focus guide was used to guide the discussion with seven purposively selected informal caregivers which lasted about one hour. One of the authors (NO) who is experienced and has publications in qualitative research moderated the focus group discussion. The discussants were allowed to discuss freely on what constitute their burden of care and how it impacts on their quality of life. The moderator asked other questions and used probes when necessary to stimulate the discussion. The discussion was recorded with audio recorder and notes were taken by an independent observer. The recorded information from the discussion was transcribed verbatim by a transcriptionist. Content thematic analysis was used to analyse 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 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 |

Level of Burden among Participants

Participants with a ZBI ≤ 20 were classified as low burden, while participants with a ZBI ≥ 21 is classified as high burden. Six participants (17.6%) had low level of burden, while 28 participants (82.4%) had 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 |

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

| Questions | Never | Rarely | Some Times | Quite Frequently | 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) |

Table 4: SF-36 domains.

| SF-36 Domain | Median | Upper Quarter | Lower quarter | Interquartile range |
|------------------------------------|--------|---------------|---------------|---------------------|
| Physical health component | | | | |
| Physical functioning (0-100) | 90.00 | 95.00 | 75.00 | 20.00 |
| Bodily pain (0-100) | 80.00 | 100.00 | 57.5 | 42.50 |
| General Health (0-100) | 72.50 | 90.00 | 60.00 | 30.00 |
| Physical role functioning (0-100) | 100.00 | 100 | 25 | 75.00 |
| Mental health component | | | | |
| Mental Health (0-100) | 78.00 | 89.00 | 66.00 | 23.00 |
| Social functioning (0-100) | 87.50 | 100.00 | 46.88 | 53.12 |
| Emotional role functioning (0-100) | 95.00 | 100.00 | 24.97 | 75.03 |
| Vitality (0-100) | 67.50 | 80.00 | 50.00 | 30.00 |

Quality of life of Informal Caregivers of Spinal Cord Injured Individuals

The 36 items on the quality of life questionnaire was divided into 8 domains: Physical functioning, General health, Mental health, Physical role limitation, Emotional role functioning, bodily pain, Social functioning and Vitality. These domains were further averaged and divided into two components. Physical component consists of Physical functioning, general health, Bodily pain and Physical role limitation. The mental health component consists of Mental health, Emotional role functioning, Social functioning and Vitality. The median (Interquartile) for physical functioning is 90.00 (20.00), 82.00 (42.50) for bodily pain, 100.00 (75.00) for physical role functioning, and 67.50 (30.00) for vitality (Table 4).

Burden and Quality of Life

A negative correlation was observed between burden of care and all the domains of quality of life except on physical role functioning. There was no significant relationship between the burden of care and all the domains of the physical mental health component. Only one of the mental health components of quality of life (vitality) had a significant association with the burden of care (Table 5).

Table 5. Relationship between Burden of care and Quality of Life using Spearman rank correlation

| Burden*SF-36 Component | P | P-value |
|----------------------------|-------|---------|
| Physical health component | | |
| Physical functioning | -0.22 | 0.21 |
| Bodily pain | -0.25 | 0.15 |
| General health | -0.14 | 0.44 |
| Physical role functioning | 0.04 | 0.83 |
| Mental health component | | |
| Mental health | -0.21 | 0.22 |
| Social functioning | -0.32 | 0.07 |
| Emotional role functioning | -0.07 | 0.70 |
| Vitality | -0.44 | 0.01* |

*Is less than P value

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

Qualitative study to further explore the burden of care and its association with the quality of life of informal caregivers of spinal cord injured individuals in Nigeria using focus group discussion was conducted. During the discussion, burden of caregiving during admission, health challenges, 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 purpose of 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 patient are summarized in Table 6. Participants were asked questions in relation to the aim of the study. This article reports information received from participants in relation to level of burden and the impact of caregiving on informal care givers.

Impact of burden of care on quality of life

The burdens associated with caring for patients often affect the quality of life of caregivers in a myriad of ways. Most discussants explained how their lives have been severely affected especially their health, social life, sexual life, family life, psychological and emotional life.

Health challenges associated with burden of care

Most of the discussants admitted to suffering from one health challenge or the other caused by the burden of care for their loved ones. Some with previous ailments got exacerbated due to the burden of care while some developed physical and mental fatigues, malaria, high blood pressure (BP), forgetfulness, insomnia, etc. Some of their excerpts were:

“In fact, the challenges are not the... when this one happened, I discovered that it is not that the person that is sick, that is having challenges even the person that is caring for the sick person is also a sick man.” (Participant 3)

“What I mean is that sometimes ago I myself have been facing some sickness, some ailment challenges that I’m patching up at home like high BP. I’m saying that I’ve been facing that challenges myself at home. That is what I’m trying to say that I don’t expect myself to do much for her the way I’ve done because of those challenges I always say I cannot do this, I don’t want to stress but

when I reach this place if there is anything to call stress, the stress here is more than what I can explain.” (Participant 3)

“The challenges I have experienced since we came here in July/ august, the problem here is too much. Going up and down, they won’t allow someone to sleep here, they will send someone away to go and sleep at emergency. All these problems one day I was sick, I was feeling cold. All these problems made me sick.” (Participant 6)

Social impact

Respondents expressed how the burden of care had affected them socially. Some mentioned social isolation and lack of time to unwind as major negative impact to their lives. Others mentioned their lack of confidence on the ability of the nurses to care for their loved ones in their absence made them to lose precious moments they would have used to socialize a little. Some equally mentioned the effect it had on their jobs and how they have been coping. Quotes from the discussions:

“It affects me seriously. In fact, it affects my social life. I’m a civil servant and I can’t go to office, it’s only God that has helped me because where I work, they have understanding, my unit I’m the head if not I was thinking will I be giving them excuses every time and I can’t leave the job.?” (Participant 7)

“I no longer do that, because after stressing yourself since morning, I can’t go out again. Church is my own work; I can’t do it again. People are just complaining in church. I’m a church worker (pastor) I can’t do anything again. Will I leave my husband and say I want to go for revival or evangelism? Even when they call from church, I feel somehow that God why me, what’s happening? All these are affecting me; I don’t have time to go out with my friends. If I say I want to leave my husband in the ward and go out, he will start crying as if the world wants to come to an end. If I say I want to do this he will say please don’t go, he knows that the nurses will not attend to him if I go.” (Participant 5)

“It affects my social life with regards to going to party because I have to take care of my wife, so because is a one man one machete. For instance, I usually come to physiotherapy twice in a week. I am lucky because I’m a teacher so they give me two days permission so but with that permission after I finish from this physiotherapy I will go straight to the school. I will continue begging the students, please o don’t be angry with me. So, this is what happened. I have to continue teaching them, instead of leaving them exactly 2 o’clock, I have to spend 40 minutes extra time. I have to so that it won’t affect them.” (Participant 4)

Impact of burden of care on psychological and social functioning.

Some mentioned forgetfulness, lack of appetite, overwhelming sadness, social isolation and emotional traumas as major effects experienced. Quotes from the discussions:

“It is affecting me. Sometimes I will be holding something in my hand and still be looking for it. I’m acting like someone that has psychological issues. Because I’m not happy, my whole body is affected because I don’t, especially when I’m looking at my child and he does something, my heart will just skip, to the extent that sometimes I can’t eat. I don’t even know how I’m feeling. I’m not

happy at all.” (Participant 2)

“The stress I underwent; this is my third week I cannot even comprehend the stress talk less of narrating the story. I had psychological stress. Even the psychological stress is even much more than the physical stress.” (Participant 7)

“Most of the time, I walk pass where I’m going or I go to the wrong direction. It’s a separate place I’m going it will take me time to remember. Yesterday morning I lock my car key inside the car. That’s why I said I pity those who don’t stay in Ibadan. Thank God I was in Ibadan I had to call home to get a spare key, before it was sent and I opened the car. As it is, it has affected my social life. For instance, now I’m wearing bathroom slippers and while at home in my compound, outside the gate hardly do I ever wear bathroom slippers out and now by foot, it is painning me.” (Participant 7)

Emotional impact

Caring for SCI patients can be tiring and traumatic due to the length of time involved. Discussants expressed the emotional traumas they went through not only from long hours of stress but also from uncaring health workers. Most resorted to self-medication to treat their health challenges while attempting to care for their sick ones. Others mentioned the security threats they faced while seeking a place to sleep. Responses from some respondents:

“As your patient is on the sick bed, you that is moving up and down you are even on sick movement because I can’t call it bed, but your sickness is somehow dynamic in such a way you are carrying your sickness and you will be trying to keep it to yourself, but one day I think it is dawn on me that I’m very sick. I think I went, I said maybe I can confide in a nurse to help me take my BP. I told one nurse, she said I don’t know GOP. I said where is GOP that they can’t do such a thing here o that unless you go to GOP? I said that it’s alright; you are not at fault I’m the one asking you. Then I went to that GOP truly, I sat there, then when my staying there was affecting my patient, I had to go to one of the doctors there. I said please this is what I’m passing through; he said well I should enter there and see one of the doctors. Is there no norm or procedure of meeting doctor here? He didn’t answer me. Then I know what to take, I know how I’ve been managing myself, but I don’t want to take that prescription into my hand and I think because of the stress that I passed through, other things might have come up then I left there.” (Participant 3)

“Then the security here is not tight enough at all. They steal phone from people, patient. One man had to be crying outside. I don’t know why it’s like that. At night you won’t see any security person walking around. Even when I sleep in my car, I’m a little bit scared and no security person has ever come to ask me what I’m doing inside the car or do they even notice that I sleep inside the car so I purposely go under the street lights. In this hospital you must always be with money because you don’t have choice. If you withdraw money before you know it, it is finished. Right now, as I’m talking, I have paid drug deposits that has wasted. Should money be wasting in this kind of condition? We are in and they won’t refund it and I purposely left it because of the stress involved.” (Participant 7)

Sexual deprivation

“There is no how there won’t be feeling. My wife knows that I like women and I like to have sexual intercourse. She pities me that my husband does not have another wife because even if I can’t sleep, the moment I have intercourse, I will sleep back. Actually, I will sleep, it is a medicine for sleeplessness for a man, I don’t know, for a woman.” (Participant 4)

“Even if someone does not feel it, it affects because this thing is a natural instinct that has health benefits. Some people after working tirelessly and cannot sleep, on seeing his wife, he will sleep and wake up and his body will be relaxed and in fact according to what I read, it affects women more than men. That a woman should not have intercourse, regular intercourse, its effects on women more than men. So, it affects me; although, the atmosphere of the situation does not allow someone to remember.” (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 |
|---------------------------|---|
| Impact on quality of life | Health challenges as a burden of care |
| | Social impact |
| | Psychological and social burden of care |
| | Emotional stress |
| | Sexual deprivation |

Discussion

The finding on the distribution of the participants in this study is similar to a previous study where most informal caregivers were females; being wives or sisters [14]. However, a study in Iran reported more male informal caregivers than female [15]. This may be because of the religious belief in Iran where women are not generally involved in activities in public places.

It is important to state clearly at this juncture that we found conflicting results between the quantitative and qualitative results as regards quality of life of informal caregivers. Quantitative study showed that only vitality in the mental health domain was affected negatively while qualitative study showed serious and detrimental impact of burden of care on quality of life of informal caregivers. It is important to note that in Nigerian culture, people are generally not expected to write negatively about the burden they bear for their relatives or how it affects them negatively. Documenting such could be seen as complaining and not playing ones’ role in both nuclear and extended family system. Nigerians are also very religious as such documenting negative things about one’s health is not acceptable as one is expected to reject such negative things such as poor mental health, poor physical health and poor social

health. Therefore the quantitative component of the study revealed that the quality of life was not affected by burden of care except in vitality but during focus group discussion where the participants were told to talk freely and were probed further, they decided to open up and discuss freely about their pain and concerns while caring for their relatives with spinal cord injury. Excerpts seen in the results of the qualitative study shows how concerning the issues raised were to informal caregivers therefore the authors have decided to pay particular attention to the findings of the qualitative study in this paper.

This study found out that majority of the participants developed health challenges while caring for individuals with spinal cord injury. This finding is similar to studies in other countries [16-17]. The plausible reason for this could be due to the fact that there is no provision of accommodation for the informal caregivers during the phase of acute care for individuals with spinal cord injury, resulting in caregivers having sleepless night and inadequate rest, leading to associated health issues like hypertension, body pains and weight loss.

Majority of the participants reported that the burden of care impacts on their emotions. A study in United State of America, suggested that intervention strategies that target both the informal caregiver and the individual with spinal cord injury are promising strategies to prevent emotional distress that may lead to mental disorders [18]. Even though we could not ascertain if there is yet development of interventions strategies that target both the individuals with spinal cord injury and their informal caregivers even in the developed countries. However, this study recommends that there is a need for research, focusing on identifying the interventions strategies that will target both individuals with spinal cord injury and their informal caregivers in developing countries.

A review by Lynch & Cahalan, [19] reported that the burden of care have negative impact on the social aspect of the quality of life of informal caregivers of individual with spinal cord injury. This is in agreement with the findings of this study, which also revealed the impact of burden of care on their social functioning, especially the job of the caregivers, which serves majorly as their source of income, and when the income dwindles, it limits them in the provision of adequate care for the patient and themselves.

A study by Mauvais-Jarvis et al., [11] reported a need for health care providers to consider sex as one of the contextual factors probed during clinical reasoning, as sex is a modifier of health and diseases. This study found out that sexual deprivation was a major concern to the participants, which no other study including in the developed countries has reported. Sexual deprivation is a serious challenge which could place psychological distress on the informal caregivers and lead to infidelity in their marital homes, limiting the attention of the informal caregivers to the care of individual with spinal cord injury during the rehabilitation phases.

Conclusion

The study revealed that the burden of care experienced has impact

on the mental health component (vitality) of quality of life of caregivers of individuals with spinal cord injury, and it affects their psychological, social, emotional, family and sexual functioning.

Informed Consent

All participants were informed about the purpose of the study and that participation in the study was voluntary and could be cancelled at any time for any reason. Consent to participate was given by completing the questionnaire. All participants were anonymous; i.e., no names or personal identification number was collected.

Acknowledgement

Our profound appreciation goes to the management of University College Hospital, Ibadan and College of Medicine, University of Ibadan for the permission granted to conduct the study within their locations.

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