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# PATTERN OF CAREGIVING BURDEN IN CAREGIVERS OF GERIATRIC POPULATION SEEN IN FEDERAL MEDICAL CENTRE, OWERRI, IMO STATE NIGERIA.

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## ABSTRACT

**Aim:** To assess the pattern of caregiving burden among caregivers of geriatric population

**Methods:**
A hospital based cross-sectional study was conducted for 215 caregivers with their respective elderly patients in the General Outpatient Clinic of the Federal Medical Centre, Owerri, Nigeria. Data were collected using the Modified Caregiver Strain Index (MCSI) and self-prepared socio-demographic sheet. Data were analysed using SPSS V.20. Descriptive statistics was employed to analyse the data.

**Results:**
In this study, the mean age of the caregivers was 40.62±15.75. Majority of the caregivers were informal caregivers, females, married, from monogamous families, had family size ≤ 5, attained tertiary level of education, employed, resident within the State, spent <6 hours/day caring for their care recipients, had rendered care to the patients for ≤ 3 months and had no other sick persons they cared for. The mean age of the care recipients was 68.03±6.25 years. Majority of them were aged 60-69 years, females, widows/widowers, had no formal education, unemployed, had been ill for ≤ 1 year, had cardiovascular type of illness and had no co-morbidity. An overall burden prevalence of 98.6% was reported amongst the caregivers; however, majority of the respondents (70.2%) had mild/low burden of care.

**Conclusions:**
Most caregivers of elderly patients experience burden of care. Our findings highlight the need to raise guidelines for health care professionals on the practical interventions aimed at identifying burdened caregivers and improving their caregiving experiences.

## INTRODUCTION

Population aging and the growing prevalence of chronic health conditions among the elderly are straining healthcare budgets, families and social networks that provide caregiving support.[1,2] Globally, the burden placed on caregivers will grow as the world population ages.[1]

The term "caregiver" refers to anyone who provides assistance to someone else who is, in some degree, incapacitated and needs help or anyone who routinely helps others who are limited by chronic conditions.[3,4] "Formal caregivers" are volunteers or paid employees connected to the social service or health care systems. "Informal caregiver" or family caregiver is broadly defined and refers to any unpaid relative, partner, friend, or neighbour who has a significant relationship with, and who provides a broad range of assistance for, an older adult or an adult with chronic or disabling conditions.[4,5] Informal caregivers are the primary type of caregivers for older adults.[1]

These are usually family members who are primarily women, such as a daughter or daughter-in-law, but can also be members of extended families.[1]

These individuals can be primary or secondary caregivers, full time or part time, and can live with the person being cared for or live separately.[6] Caregivers experience a multidimensional range of problems, often associated with their caregiving role.[7] Family caregivers often cite higher levels of perceived stress, social isolation, difficulty finding time to care for oneself, and lack of work-life balance, resulting in a negative impact to their emotional well-being.[2,8]

The United Nations (UN) defines an elder or older person as anyone aged 60 years or over while the World Health Organisation (WHO) regards anyone aged 65 years or above as an older or elderly person in the majority of developed countries. However, the age of 60 is often considered by the World Health Organisation (WHO) in low- and middle-income countries.[1,9,10]

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Providing daily care for the elderly is a new and challenging task for the family, whose members are suddenly transformed into caregivers, often without appropriate training, knowledge or support to assume this position, which involves losses to their quality of life and also to the quality of care.[1] When performing activities related to the physical and psychosocial well-being of the elderly, caregivers experience restrictions in relation to their own lives, which contribute to the onset of burden.[1] The stressors that are particularly burdensome to caregivers include managing physical care, managing symptoms and treatments, giving emotional support, dealing with fear and uncertainty about the disease and watching the patient suffer.[2,12] Burden of care is a phenomenon that can be defined as an intrinsic dilemma of the care process, including physical, psychological, emotional, social and/or financial problems.[11,13] Although the overwhelming majority of family caregivers provide appropriate care and a supportive environment for their older relatives, caregiving creates stresses that affect both caregivers and care recipients, and these stresses may trigger potentially harmful caregiver behaviours that place dependent elders at risk for abuse.[5,10,11]

Providing quality care for care recipients often requires an understanding of the caregiver's situation and needs. However, these needs are frequently not identified or addressed in the recipient's care plan.[14] In daily medical practice, the caregivers are often neglected.[2,4,15] In fact, caregivers have been described as 'forgotten patients'.[6]

Through studies like this, awareness on the prevention of elder abuse can be stimulated by physicians through identification of certain 'red flags' in caregivers such as the perception of caregiving responsibilities as a burden and perception of not receiving adequate help or support from others.[4]

The research question for this study is what is the proportion of caregivers of elderly patients with burden?

## MATERIALS AND METHODS

The study was conducted between February 2016 to April 2016 at the General Out-patient Clinic (GOPC) of the Federal Medical Centre, Owerri (FMCO), Imo State, Nigeria. T

he study population comprised of caregivers of all elderly patients (60 years and above) that attended the GOPC of FMC, Owerri. Inclusion criteria included all consenting caregivers aged 18 years or more, involved in the care of elderly patient(s) for at least one month. The caregivers, who had communication problems like hearing or speech impairment were excluded from the study. Systematic sampling method was used to recruit 215 caregivers into this study. Data was collected with a well-structured interviewer-administered pre-tested questionnaire and the Modified Caregiver Strain Index (MCSI)[16]

The questionnaire consisted of 2 parts. The first part consisted of socio-demographic information of the caregivers and other questions related to their caregiving roles (this included the caregiver's age, sex, marital status, educational and occupational status, type of care being rendered, number of hours spent caring for patient per day, relationship with the patient, location of residence, type of family and family size and presence of other patients that the caregiver renders care to).

The second part was used to assess the patient or care receiver's factors and other questions related to their clinical condition (and included patient's age, sex, marital status, educational and occupational status, type/class of illness, presence of co-morbidity and duration of illness). The care receivers were clerked and examined by the researcher using a clinical data recording form. Using this, the class of illness, presence of co-morbidity and duration of illness of the care receivers were derived.

Modified Caregiver Strain Index (MCSI)][16]- It is a tool that can be used to quickly screen for caregiver burden.[16] It is a 13-question tool that has at least one item for each of the following major domains: Financial, Physical, Psychological, Social, and Personal burden. This instrument can be used to assess individuals of any age who have assumed the caregiving role for an older adult. The MCSI has been used in Nigeria and the results are comparable to the findings in the environment where it has been validated.[17,18,19] It has a strong internal consistency (cronbach alpha of 0.90) thereby suggesting that it is highly reliable.[16,20,21] Scoring is 2 points for each 'yes', 1 point for each 'sometimes' and zero point for 'no' response; with a minimum score of 0 and maximum score of 26 points.[16,20] The higher the score, the higher the level of caregiver strain.[16,20,22] After screening the caregivers as per the inclusion and exclusion criteria, consenting respondents signed a consent form and were interviewed in a separate room in the GOPC.

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Their care recipients were also interviewed, clerked and examined. It took about 30-45 minutes to interview a caregiver, clerk and examine the care recipient. The data was then transferred into SPSS V.20 and was analyzed using descriptive statistics. The study was approved by the Ethics Committee of the FMCO. Participation in the study was voluntary and each participant was informed that their decision to participate or not, would not lead to victimization or affect his/her patient's care. Confidentiality of the respondents was maintained and full autonomy to withdraw from the study at any time was given. All highly burdened caregivers and/or those found to have dysfunctional families were counselled and duly referred to the social welfare unit of the hospital for support services.

## RESULTS

### Characteristics of Caregivers

The ages of the respondents ranged between 18-72 years while the mean age was 40.62±15.75 years. Respondents aged ≤30 years contributed to the highest population (27.9%). Females (74.4%) constituted a greater proportion of the study population compared to the males (25.6%). Females (74.4%) constituted a greater proportion of the study population compared to the males (25.6%). Married respondents constituted the highest proportion of the study population (60.9%). Majority of the respondents attained tertiary level of education (57.7%). The employed (61.9%) constituted a greater proportion of the study population compared to the unemployed (38.1%). Concerning the relationship with the care recipient, almost all of the patients were cared for by a relative (99.1%) with only (0.9%) cared for by a non-relative. Majority of the respondents were resident within the State (93.5%). With respect to the duration of caregiving, 58.1% of the caregivers had rendered care to the patients for ≤ 3 months and 41.9% of them rendered care to the care recipient for >3 months. Majority of the respondents rendered informal caregiving to the patients (96.7%). Regarding the number of hours spent caring for the patients, most of the respondents (35.3%) spent <6 hours/day caring for their care recipients while the least number of respondents (13.9%) spent the longest time (18-24 hours/day) caring for their care recipients. Majority of the caregivers (69.8%) lived with the care recipients. Concerning the type of family, most of respondents (95.3%) were from monogamous families. More than half of the respondents (59.1%) had family size ≤5 and 40.9% of them had family sizes >5. Majority of the caregivers (79.5%) had no other sick persons they cared for.

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**Table1: Characteristics of Care givers**

| Variable | Frequency | Percentage |
|---|---|---|
| **Age (years)** | | |
| =30 | 60 | 27.9 |
| 31-40 | 37 | 17.2 |
| 41-50 | 33 | 15.4 |
| 51-60 | 31 | 14.4 |
| >60 | 54 | 25.1 |
| **Gender** | | |
| Male | 55 | 25.6 |
| Female | 160 | 74.4 |
| **Marital status** | | |
| Single | 57 | 26.5 |
| Married | 131 | 60.9 |
| Separated/divorced | 13 | 6.1 |
| Widow/widower | 14 | 6.5 |
| **Educational status** | | |
| None | 23 | 10.7 |
| Primary | 24 | 11.2 |
| Secondary | 44 | 20.4 |
| Tertiary | 124 | 57.7 |
| **Occupational status** | | |
| Unemployed | 82 | 38.1 |
| Employed | 133 | 61.9 |
| **Relationship with the care recipient** | | |
| Spouse | 53 | 24.7 |
| Child | 106 | 49.3 |
| Grand child | 13 | 6.0 |
| Other relatives | 41 | 19.1 |
| No familial relationship | 2 | 0.9 |
| **Location of residence** | | |
| Within Owerri | 108 | 50.2 |
| Outside Owerri but within Imo State | 93 | 43.3 |
| Outside Imo state | 14 | 6.5 |
| **How long have you been rendering care to this patient** | | |
| =3 months | 125 | 58.1 |
| >3 months | 90 | 41.9 |
| **Type of caregiving rendered** | | |
| Formal | 7 | 3.3 |
| Informal | 208 | 96.7 |
| **Number of hours spent caring for (hours/day)** | | |
| <6 | 76 | 35.3 |

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**Characteristics of the Care Recipients**

The ages of the respondents ranged between 60-92 years while the mean age was 68.03±6.25 years. The care recipients aged 60-69 years contributed to the highest population (54.0%). This was followed by those aged 70-79 years (36.3%) while those >80 years made up the least population (9.8%). Females (61.9%) constituted a greater proportion of the care recipients compared to the males (38.1%).
One hundred and eleven (51.6%) of the care recipients were widows or widowers while (42.8%) were married and very few (2.3%) were either single or separated/divorced (3.3%). A good number of the respondents (44.7%) had no education. The respondents with secondary level of education constituted the least percentage (12.1%). Majority of the care recipients (53.5%) were unemployed. The retired respondents accounted for 27.0% of the care recipients. Those unable to work due to medical reasons (3.3%) were the least.
Most of the respondents (77.2%) had no co-morbidity. Majority of the care recipients (62.8%) had been ill for ≤1 year while the least recorded group of care recipients (6%) had >10 years as their duration of illnesses. Majority of the care recipients (42.8%) presented with cardiovascular illnesses.

## Table2: Characteristics of Care Recipients

| Variable | Frequency | Percentage |
|---|---|---|
| **Age (years)** | | |
| 60-69 | 116 | 54 |
| 70-79 | 78 | 36.2 |
| 80 | 21 | 9.8 |
| **Gender** | | |
| Male | 82 | 38.1 |
| Female | 133 | 61.9 |
| **Marital status** | | |
| Single | 5 | 2.3 |
| Married | 92 | 42.8 |
| Separated/Divorced | 7 | 3.3 |
| Widow/Widower | 111 | 51.6 |
| **Educational status** | | |
| None | 96 | 44.7 |
| Primary | 38 | 17.7 |
| Secondary | 26 | 12.0 |
| Tertiary | 55 | 25.6 |
| **Occupational status** | | |
| Unemployed | 115 | 53.5 |
| Employed | 35 | 16.3 |
| Retired | 58 | 27.0 |
| Unable to work for medical reasons | 7 | 3.2 |
| **Presence of co-morbidity** | | |
| Yes | 49 | 22.8 |
| No | 166 | 77.2 |
| Duration of illness | | |
| =1 year | 135 | 62.8 |
| >1 year- 5 years | 45 | 20.9 |
| >5 years-10 years | 22 | 10.2 |
| >10 years | 13 | 6.1 |
| Total | 215 | 100.0 |

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**Caregiver Burden**

Majority of the respondents (70.2%) had mild/low burden of care while 27.0% of the respondents had moderate burden of care. Only 1.4% was recorded for severe burden of care while those without any burden were 1.4%. The overall burden prevalence as shown below was 98.6%.

## DISCUSSION

This study reported an overall burden prevalence of 98.6% amongst the caregivers. The burden severity ranged from mild/low to severe with majority (70.2%) of the respondents reporting mild burden. Similarly, Uwakwe and co-worker in a community based study of caregivers of older patients in South-eastern Nigeria reported that 97.5% of the caregivers expressed that providing care was a very heavy burden on them.[23] The authors used the Zarit burden Interview (ZBI) but arrived at results which are in keeping with the finding of the present study.[23] It is also worth noting that another study in the same region of the country reported that a high proportion (82.4%) of stroke caregivers experienced considerable burden.[7] The authors dwelt on a specific illness type and used a different tool [Caregiver Strain Index (CSI)] but arrived at results consistent with the findings of this study.[24] One might speculate that the harsh economic condition of the nation coupled with poor support services for caregivers and their care recipients might be a contributory factor to these high figures. Sufficing to say, this high burden prevalence is not limited to the Nigerian context as foreign studies have reported figures consistent with the results of this study. A 100% burden of care was reported in a cross-sectional study in India by Bibin et al who assessed the burden of care on 60 primary caregivers of mentally ill patients.[25] The finding of Jensinya and co-workers in a study in another district of India was in consonant with the above findings. In their study, they noted that all the caregivers of the recruited schizophrenia patients had high burden in almost all the domains of the tool used in assessing their burden of care (the family burden interview schedule).[26] Similar to the result of the current study, in China, Mould-Quevedo et al reported that most of the carers of dementia patients reported mild to moderate burden.[27] However their reported prevalence of burden was lower (43%) than that reported in this study probably because they used a different tool (Chinese version of the Zarit Burden Interview) to assess the burden of care. In Ghana, Nortey et al reported a similarly high level of burden amongst the study participants.[3]

The high level of burden in the present study is attributed to multiple factors. Most of the caregivers are children of the care recipients who have other family responsibilities to cater for aside from caring for their parents, they might also be in low paying jobs despite being employed and be mostly females implied that they are saddled with the responsibility of playing dual roles of caring for their own homes and any other ill family member and caring for the present care recipient. Female gender and socioeconomic factors have been associated with burden of care and family caregivers are known to provide intensive levels of care.[28,29] Furthermore, being children of the care recipients and employed might imply inability to adjust to the intricacies of caregiving role coupled with being faced with periods of stress regarding combining work schedules and caregiving roles. Factors related to the care recipients might also attribute to the high burden experience. Majority of the care recipients being females, unemployed and with low level of education could have contributed to more burden as females are more demanding for care from their children more than men who tend to easily suppress their care needs.[3]

On the other hand, other studies have reported findings not in tandem with the result of this study. Forty per cent of caregivers were reported to be burdened in a study conducted in the USA.[30] A much lower figure (25.0%) was reported in a study in Malaysia.[31] From the foregoing, it seems that studies in developing countries report relatively higher prevalence of burden in comparison to studies conducted in more developed countries. This difference in prevalence of caregiver burden reported in these studies in comparison to the present study might be related to the availability of support services that help to lessen the pressures of caregiving in the developed countries.

## RECOMMENDATIONS

1. There is the need to raise guidelines for health care professionals on the practical interventions aimed at caring for caregivers, identifying burdened caregivers and improving their caregiving experiences.
2. Support services by the management of the study site needs to be extended to caregivers and their families and not limited to patients.

**CONFLICT OF INTEREST: NON DECLARED**

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