



SOCIAL SUPPORT TO OLDER PERSONS WITH CHRONIC DISEASES AND THE BURDEN ON CAREGIVERS IN OGUN STATE, NIGERIA.

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ABSTRACT

The importance of social support in alleviating the physical health, economic, and psychological challenges of older persons cannot be overemphasized. However, social support to older persons with chronic diseases has not been fully explored while the caregivers' burden to this category of patients is relatively unknown in Nigeria.

This study aimed to evaluate the social support available to older persons with chronic diseases and determine the burden of care on the caregivers. A descriptive cross-sectional study was carried out among 405 consecutively sampled chronically diseased older patients aged ≥ 60 years and 53 of their caregivers in two Nigerian tertiary healthcare facilities. A 32-item questionnaire that explored the patients' socio-demographics, social supports received or desired and the caregivers' burden experienced in the care of older patients was administered to the participants. The majority of the patients (282; 69.6%) were aged 60-69 years; 311 (76.8%) claimed the social support they received was from family and 278(68.6%) indicated that financial support was most desired from the government. Marginally half of the caregivers (27; 50.9%) were female and 13 (24.5%) had to resign to care for their patients. Family is the main source of social support for older persons with chronic diseases in Nigeria. The family caregivers' burden to older people with chronic diseases is huge.

Keywords: Ageing, financial, physical health, sub-Saharan

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INTRODUCTION

The importance of social support in alleviating the physical health, economic, and psychological challenges of older persons cannot be overemphasized. Social support is defined as the apparent or real resources provided by a community that engender in the beneficiaries a sense of worthiness, value and being a part of a social network [1]. Social support promotes medication adherence [2], resilience, improve both self-rated health and well-being of older persons with chronic disease conditions [3-5]. The social support may be tangible such as the provision of food, money and clothing or intangible in form of companionship, information, emotional support, and assistance with daily chores [1].

Chronic diseases pose a significant burden both in developed and developing nations. It drains the little resources available to older persons and increases their level of dependence on others [6]. Considering the high cost associated with older peoples' care in institutionalized centres as obtained in the developed countries, caregivers come as a relatively cheaper alternative in many developing countries. In many African countries including Nigeria, family members especially females or paid caregivers perform this essential role to older people [7]. However, caring for older people is associated with burdens to the caregivers.

The caregivers may experience reduced quality of life, increased emotional stress, and sometime stigmatization which generally affect their overall health and well-being and may consequently diminish the caregivers' capacity to provide optimum care [6, 8].

In 2020, Nigeria, a middle-income country with an estimated population of 10.9 million people of ≥ 60 years ranked 19th among the countries with the largest population of older people in the world [9]. Many of the older people in this sub-Saharan Africa country are, however, with chronic diseases or disabilities with no special social security specifically targeted at them in the country [10]. In most cases, older persons in Nigeria access healthcare through out-of-pocket payments and are not covered by the National Health Insurance Scheme [11]. In the African traditions, social support for older persons was considered a primary responsibility of the family *albeit* informally. However, evidence suggests that this support has dwindled over time due to the disintegration of traditional family structures and economic hardship in many African nations including Nigeria [10]. There is, therefore, a need to investigate the available social support to older persons and the burden associated with caregiving in Nigeria. This study aimed to evaluate available social support to older persons with chronic diseases and the caregivers' burden in Nigeria.

MATERIALS AND METHODS

Study design and study areas

This was a descriptive quantitative cross-sectional survey and medical chart review among consecutively selected older patients and their caregivers at the Federal Medical Centre (FMC), Abeokuta and Olabisi Onabanjo University Teaching Hospital Sagamu (OOUTH), both in Ogun State, Nigeria. The hospitals provide tertiary healthcare services and are referral centres for many healthcare facilities in the southwest region of Nigeria.

Study population/eligibility criteria

Consecutively selected older patients aged ≥ 60 years with at least one chronic disease, that had attended medical outpatient clinics for at least one year, and their accompanying caregivers were included in this study. The caregivers must have been taking care of the patients for at least 3 months before the study. Eligible participants that were not available during the data collection period (3rd December 2019- 2nd February 2020), had no record of medications received and those evaluated during the pilot stage were excluded.

Sample size estimation

The sample size was determined using Cochran's Formula [12]. Using an available population of 1682, a 5% margin of error, a response rate of 50% and 95% confidence level, a sample size of 384 was estimated.

Questionnaire design and Data collection technique

A 32-item researcher-administered questionnaire developed after the review of some studies [2,3,6], was used to garner the older patients' responses concerning the types of social supports they received. Caregivers that accompanied the patients were asked to respond to questions on the burdens they experienced in the care of the older patients. The questionnaire was sectioned into three. Section A comprised of eight socio-demographic questions including age and gender. Section B comprised 11 questions that explored the types of social supports received or desired by the older patients. Section C comprised 13 questions that evaluated the caregivers' perspectives on the burden experienced in the care of older patients with chronic diseases. The questionnaire was validated by an academic and piloted among 20 older patients with chronic diseases. The questions were modified based on the outcomes of the validation and pilot study to remove ambiguity and enhance clarity. The final questionnaire with a Cronbach's alpha value of 0.82 was administered to the participants. Older patients without or limited incapacitation answered the questions on their own

while caregivers responded to the questionnaires on behalf of their patients with serious incapacitation. In the latter group, the caregivers also responded to Section C of the questionnaire on caregivers' burden. Medical chart review was carried out to evaluate the diagnosis and the medications received by the older patients, and to ascertain the correctness of the patients' and caregivers' knowledge of the patients' conditions and medication use. The hospital medication price list was used to calculate the total cost of medication for each patient. The average monthly cost of medications for the patients was calculated in the Nigerian currency and converted to the United States dollars at ₦480/\$.

Data management and statistical analysis

The data were manually cleaned and inputted into Microsoft Excel Software 2016 (Microsoft, Corp.) for easy sorting. The data were analyzed using the Statistical Product and Services Solution version 23 (IBM, Corp.). Respondents with missing socio-demographic and diagnoses in their records were removed before the analysis. The data were primarily analyzed using descriptive statistics including frequency and percentage. Chi square test was used to evaluate differences of opinion between the caregivers and the patients. Associations between participants' socio-demographic and variables of study interest were determined using the Chi-squared test or Fisher's exact as appropriate. $P < 0.05$ was considered statistically significant.

Ethical clearance

The purpose and the requirements of the study were explained to the participants and their written informed consent was obtained before the commencement of the study. The information obtained from the participants was kept confidential. This study received approval from the Ethics committees of OOUTH under the reference OOUTH/HREC/329/2020AP and the (FMC), FMCA/470/HREC/01/2020/18.

RESULTS

Of the 432 copies of the questionnaire distributed, 405 were analyzed giving a response rate of 93.8%. Three hundred and fifty-two (86.9%) patients responded to the questionnaire on their own while 53 (13.1%) caregivers answered on behalf of their patients. Majority of the patients (69.6%) were aged 60-69 years (Mean age was 68.08 ± 6.36 years) and married (315; 77.8%). See Table 1 for details.

Table 1a: The social and clinical characteristics of the patients (N=405)

Variable	Grouping	Frequency	Percentage
Age	60-69 years	282	69.6
	70-79 years	96	23.7
	80-89 years	27	6.7
Gender	Male	209	51.6
	Female	196	48.4
Marital status	Single	18	4.4
	Married	315	77.8
	Widowed	72	17.8
Educational qualification	No formal education	106	26.2
	Primary	91	22.4
	Secondary	106	26.2
	Post-secondary	102	25.2
Occupation	Private	16	3.9
	Public	46	11.4
	Self-employed	251	62.0
	Retired	92	22.7
Self-health rating	Good	46	11.4
	Average	256	63.2
	Poor	103	25.4
Period of diagnosis	<1 year	83	20.5
	1-5 years	272	67.2
	6-10 years	46	11.3
	>10 years	4	1.0
Respondents	Patients	352	86.9
	Care-givers	53	13.1

Table 1b: The social and clinical characteristics of the caregivers (N=53)

Variable	Grouping	Frequency	Percentage
Age	<20 years	6	11.3
	21-29years	12	22.6
	30-39years	28	52.8
	40-49 years	5	9.4
	50-59 years	2	3.8
Gender	Male	26	49.1
	Female	27	50.9
Marital status	No formal education	0	0.0
	Primary school	1	1.9
	Secondary	34	64.2
	Post-secondary	18	34.0
Employment status	Employed	38	71.7
	Unemployed	15	28.3

Relationship	Direct family relation	38	71.7
	Grand child	13	24.5
	Friend	2	3.8
Duration of care	3months<1 year	42	79.2
	1-5 years	7	13.2
	6-10 years	4	7.5
Self-health rating	Good	49	92.4
	Average	4	7.6

The most diagnosed chronic diseases among the patients were hypertension alone (138; 34.1%) and cardiovascular accident alone (88; 21.7%) (Table 2).

Table 2: The distribution of chronic diseases among the participants

Chronic disease(s)	Frequency	%
Hypertension	138	34.1
Hypertension + Diabetes mellitus	56	13.8
Hypertension + Arthritis	6	1.5
Hypertension + Dementia	1	0.2
Hypertension + Cerebrovascular accident	33	8.1
Hypertension + kidney disease + Diabetes Mellitus	10	2.5
Arthritis	32	7.9
Dementia	8	2.0
Diabetes Mellitus	29	7.1
Cerebrovascular accident	88	21.7
Cerebrovascular accident + Diabetes Mellitus	2	0.5
Cerebrovascular accident + Dementia	2	0.5

Table 3 presents the ten most frequently used medications among the participants. Amlodipine was the most frequently used medications among the participants (82; 20.2%). Majority of the patients (362; 89.4%) were on at least three medications.

Table 3: The Medication utilization patterns among the respondents

Medication	frequency	Percentage
Methyldopa	35	8.6
Amitriptyline	42	10.4
Amlodipine	82	20.2
Pregabalin	20	4.9
Clopidogrel	16	4.0
Lisinopril	23	5.7
Rosuvastatin	16	4.0
Furosemide	16	4.0
Misoprostol	19	4.7
Metformin	52	12.8
Others*	84	20.7

Others include simvastatin, nifedipine, risperidone, diclofenac, macrogol, warfarin and candesartan. The average monthly cost of medication for the patients was ₦1730 (\$3.60) (R=₦300-₦6540). Majority could sometime (227; 56.0%), most time (86; 21.2%) every-time (49; 12.1%); rarely (43; 10.6%) afford the medication cost. There was a significant difference in opinion between patients and caregivers concerning the affordability of the medication (p=0.003). Many patients (221; 54.6%) claimed to borrow, 90(22.2%) beg, 90(22.2%) sell personal properties while the remaining 4(1.0%) delay other payments to raise money for medications.

The majority of the participants claimed the social support they received was majorly from family (311; 76.8%), friends (66; 16.3%), NGO (11;2.7%) and religious groups (17; 4.2%). Many participants (251; 62.0%) ranked emotional support as the type of support

they most received, followed by companionship (102; 25.2%), financial (48; 11.9%) and informational (4; 1.0%). The majority believed financial support (375; 92.5%) was the most needed followed by emotional (15; 3.7%), informational support (9; 2.2%) and companionship (6;1.5%). There was no significant difference between the patients and the caregivers' responses ($p=0.098$) on this. More than two-thirds of the respondents (278; 68.6%) indicated that financial support was most desired from the government.

The challenges faced by caregivers in caring for older persons with chronic diseases are as presented (Table 4). The caregivers' mean age was 32.24 ± 8.32 years (16-52 years); marginally half were female (27; 50.9%); 52 (98.1%) had at least secondary education; 51(96.2%) were family relations while the remaining 2 (3.8%) were friends. Many of the caregivers (33; 62.3%) could only care for the patients for another 1 year; 10(18.9%) for 2 years, 4 (7.5%) for 3 months while only 6 (11.3%) could care for the patients for more than 2 years.

Table 4: Assessment of the caregivers' burden (N=53)

Question	Yes n(%)	No n(%)	Not sure n(%)
Are you willingly caring for the patient?	53 (100.0)	0(0.0)	0 (0.0)
Do you live in the same house as the patient?	50 (94.3)	3(5.7)	0 (0.0)
Do you have to resign to care for this patient?	13 (24.5)	40 (75.5)	0 (0.0)
Do physicians follow up on your patient?	39(73.6)	14(26.4)	0(0.0)
Does the caregiving duration affect your emotional health or general health?	48 (90.6)	4 (7.5)	1 (1.9)
Do you have other relatives that are under your care	34 (64.2)	18 (34.0)	1 (1.9)
Do you think you do not have enough time for yourself because of time spent in caring for the patient?	44 (83.0)	8 (15.1)	1 (1.9)
Do you think your patient dependence on you is beyond your capability?	37 (69.8)	10 (18.9)	6(11.3)
Do you feel uncomfortable inviting your friends to your house because of your patients' presence?	34 (64.1)	15(28.3)	4 (7.5)
Do you suffer from any chronic disease?	8 (15.1)	45 (77.4)	4 (7.5)

DISCUSSION

This study evaluated the social support to older persons with chronic diseases and the burden associated with caring for this cohort in Nigeria. The study found that family and friends are the main sources of social support to older persons. The caregivers suffer both emotional, financial and social strains in the course of caregiving to older persons with chronic diseases in Nigeria.

Consistent with previous studies in Turkey and Nigeria [2, 3], the majority of the participants in this study claimed that the social support they received was from families. It is startling that none of the participants mentioned government support. This is probably due to a lack of awareness of the intangible government support to their well-being through healthcare financing.

The little financial support from the family is understandable and could be partially attributed to the general economic hardship in Nigeria. Previous studies have reported a similar finding among Nigerians with hypertension and diabetes [2, 13]. The finding of this study could account for the average self-health rating by the majority of the participants.

Social supports improve the self-rated health of older people when it is adequate both in quantity and quality [4, 5]. The filial support received by the participants was inadequate and might not be maximally beneficial to the recipients. This is because, while the participants required and desired financial support majorly, the available support from the family were mainly emotional and informational. Evidence, however, suggest that for the social support to be

maximally beneficial, the available social support should match the desired support by the beneficiaries [14]. The observation of this study could probably account for the average self-rated health by the majority of the participants.

Medications constitute a large fraction of healthcare costs in many health care systems worldwide, and for older people specifically [15]. In this study, the average cost of medications per month prescribed for the participants was \$3.60 which is about 6.0% of the national minimum wage (\$62.5) in Nigeria. This was not affordable to the majority of the participants and they had to devise mechanisms *albeit* catastrophic such as borrowing, begging and selling their properties to fund their medication bills. The catastrophic health spending may impair older patients' access to healthcare and increase their susceptibility to inadequate care [16].

Based on their catastrophic spending on healthcare, it is not surprising that many participants were desirous of financial support from the government. Previous studies in Nigeria had indicated that one of the unmet social needs of the older person in Nigeria is financial support from the government [2, 17]. The observation of this study, however, contradicts the spirit of the African Union strategic plans for the implementation of the 2002 United Nations Madrid International Plan of Action on Ageing that recommend "to improve access to health care for the older people by removing financial barriers and creating provisions for the social protection of older people" [18]. To relieve older people of financial burdens in the treatment of chronic diseases, social support packages including universal free health care or a waiver on medication fees should be considered. Alternatively, expansion of the National Health Insurance Scheme to cover older people should be aggressively pursued.

In this study, the majority of the caregivers were living in the same house with their patients. Studies indicate that living in the same house with a patient increases caregivers' burden since most of the house chores will be done by the caregivers and they may also participate directly in the physical care of their older patients including administration of medications to cognitively impaired patients [8]. Another finding of this study is the involvement of teenagers aged 16-17 years in the care of older patients. Although this may be culturally acceptable, the practice can endanger the future of teenagers and nations since their schooling or apprenticeship may be hampered.

Considering the burden associated with caregiving [19, 20], it is surprising that nearly a quarter of the caregivers in this study had to resign from their duty posts to care for their older patients. The caregivers may often have to pay for transportation to health facilities, procurement of medications and medical supplies for their patients which increases their financial

solvency. It is estimated that over 18 billion hours of unpaid care were provided by the United States family caregivers of dementia patients in 2014 [21]. Religious and cultural beliefs that emphasise the sanctity of caring for older persons especially parents could have impacted the participants to behave in this manner.

In this study, the caregivers perceived that their mental and physical health is affected consequent on their caregiving role to older people with chronic diseases. This observation is consistent with previous reports on caregivers' burden [6,22]. Mental ill-health among caregivers can lead to abuse of older persons in their care if not quickly identified and resolved [23]. Healthcare providers including Nurses and Social workers are in a good position to identify and evaluate the mental health burden of caregivers and provide interventions to ameliorate this unpleasant effect [24].

In this study, many of the caregivers could only care for the patients for 1 year while marginally above one-tenth could care for the patients for more than 2 years. This finding is significant and probably indicates the tolerance threshold of the caregivers. Studies have indicated that caregiving of more than 2 years duration was associated with higher burdens for caregivers [20], while longer than 3 years is associated with higher risks of depression among the caregivers [24]. This study finding probably implies that family caregivers' commitment to the care of their older patients should not be taken for granted. The caregivers' burden if unresolved may impede their capacity to continue with the role. Governments, therefore, need to design and implement policies that will adequately address the mental health and financial needs of the caregivers.

Strength and Limitations

The study was carried out in two urban tertiary health facilities in Nigeria but it is recognized that many older people live in rural areas and visit other layers of healthcare delivery. Their perceptions of social support and the caregivers' burden may therefore be different. Despite this limitation, this study highlights the enormity of the challenge faced by older people and their caregivers in Nigeria and the areas where government interventions are most desirable.

CONCLUSIONS

Family members are the major source of social support for older persons with chronic diseases in Nigeria. This filial support is, however, inadequate and might not be maximally beneficial to older patients. The older people received mostly emotional support but many would desire financial support from the government. The emotional and general well-being of family caregivers are affected by the burden of caregiving to older people with chronic diseases. There is, possibly, a caregivers'

tolerance threshold after which older people's abuse and neglect may set in.

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Conflict of interest

Authors declare there is no conflict of interest in this study

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