

Relationship between Cost of Treatment of Schizophrenia and Caregiver Burden in Northern Nigeria

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ABSTRACT

Schizophrenia is a costly illness exacting its toll not only on the affected victims but also on the caregivers as well. Studies on cost of treatment (COT) of schizophrenia in Sub-Saharan Africa are few, and even fewer are studies that sought to assess the relationship between the cost of care and its relationship to the burden of care among caregivers. A total of 270 patients with schizophrenia comprising 90 patients receiving acute phase treatment, 180 receiving maintenance care, and 165 caregivers participated in this study from a tertiary institution in Northern Nigeria. The Mini International Neuropsychiatric Interview Plus was used to make diagnosis of schizophrenia among patients, and anxiety disorder and depression among caregivers; a modified cost of illness questionnaire to estimate the COT; and the Zarit Burden Questionnaire to assess the level of burden among caregivers. Findings revealed mean age of participants to be 33.04 years (SD±9.743). Majority were singles (45.6%) and of low socioeconomic status (SES) (88.5%). COT had a statistically significant relationship with participants' illness presentation, SES, Zarit Burden Score and Length of Caregiving. Mean monthly estimate of direct cost of treatment per patient was ₦25,398.19 (\$133.67) for acute patients and ₦3087.21 (\$16.25) for stable patient. Regression analysis showed length of caregiving and SES as predictors of direct COT. COT was intricately linked to burden of care and length of caregiving. Out-of-pocket payment predominated. Government intervention in subsidizing COT will help reduce the burden of care, the frequency of relapse and the complications of prolonged non-treatment

Keywords: Burden of Care, Cost of treatment, Nigeria, Schizophrenia,

BACKGROUND:

Schizophrenia begins early in life, causes substantial and long-lasting impairments, and makes heavy demands of hospitals and caregivers. The financial cost of the illness is enormous, exacting its toll on both government

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institutions and caregivers.¹ To estimate the cost of schizophrenia is to appraise and assess the consequences of failure to treat, both on family members and the community. Cost of illness (COI) includes health sector costs (direct cost), the value of lost productivity (indirect cost) and the cost of pain and suffering (Intangible cost). Estimating the economic burden (or cost) of illness on society is essential in formulating, planning, prioritizing and financing projects and policies that will impact positively on the wellbeing of the people at costs that is affordable and sustainable for both government and the people.¹⁻³ With the progressive decrease in the number of hospital beds for the mentally ill as a result of deinstitutionalization and a shift to community mental health care, a substantial burden of care for people with mental illness fell on their families. The World Health Organization estimates that 40% to 90% of the patients with schizophrenia live with their families.⁴ Caregivers not only experience the burden of care-giving in terms of its financial and physical demands, but also the stigma and discrimination experienced by the patients themselves.^{4,5} Some studies have been conducted in Nigeria on burden of care among caregivers of patients with Schizophrenia. The study by Yusuf *et al.*⁶ involving 129 caregivers of schizophrenia patients used the Zarit Burden Interview to assess the burden of caregiving. Their findings reveal a predominance of female caregivers of whom 47.3% had high level of burden. The study also found an association between care burden with a family size of five and above, urban dwelling, as well as consequences of stigma, negative behaviour by the patient and financial constraints. Igberase *et al.*⁷ on the other hand in Midwestern Nigeria used the Burden Questionnaire, and found a high level of caregiver burden that was associated with low educational status and unemployment among the patients. The study also showed that about half of the caregivers were parents of the patients. Much of the burden of care-giving

was found to result more from effect of financial drains and stigma.⁷ Studies on COI generally are sparse in developing countries and more so, studies that seek to assess the relationship between cost of treatment of schizophrenia and burden of care in Nigeria. A study on financial cost of treating stable out-patients with schizophrenia by Suleiman *et al.*⁸ about two decades ago in Southwest Nigeria, was conducted at a time when atypical antipsychotics were unavailable and modified Electroconvulsive Therapy (ECT) was unusual. Additionally, the Naira equivalent of the US dollar during that study was N82 in contrast to N190 during the current study. It will be gratifying to compare their findings with those of patients receiving acute phase treatment and to analyze the impact of symptoms and financial drains on caregivers. This study therefore aimed at evaluating the relationship between the cost of treatment of schizophrenia and caregiver burden in Northern Nigeria. The study by Oloniniyi *et al.*⁹ conducted a decade ago, assessed the economic cost of schizophrenia among stable patients. Their study looked at the enormity of the direct and indirect cost of care but did not consider the effects of these costs on the caregivers

MATERIALS AND METHODS

This study is part of a larger study which sought to assess the relationship between cost of treatment of schizophrenia with other variables such as cognitive impairment among patients; symptoms profile and severity; and burden of care.

Study Location

This study was carried out at Ahmadu Bello University Teaching Hospital, a tertiary hospital located in Shika-Zaria of Kaduna State, Nigeria. At the time of this study, the psychiatry department of the hospital had three consultant psychiatrists, six senior registrars and seven registrars. The male and female

psychiatric wards and the psychiatric clinics were used for data collection

Study Population

These included: Male and female patients aged 15 years and above with a diagnosis of Schizophrenia (taking into consideration the typical epidemiological age of onset for schizophrenia) admitted or attending the psychiatric clinic; and caregivers of patients with schizophrenia. There were two (2) patient groups: Group I: patients diagnosed with schizophrenia (either first presentation or having a relapse) and receiving acute phase treatment.^{4,10} Group II: patients diagnosed with schizophrenia who had been stable in the preceding six (6) months and were on maintenance treatment.^{4,10} The caregiver was any person (relative or paid help) who lived with or frequently visited the patient and was knowledgeable about the patient. Patients were assessed once a month for three months. The mean monthly cost was then evaluated. Some stable patients who had more than one-month appointment were assessed but taking into consideration all direct costs accruing over a month period. NB: Not all stable patients were accompanied by a caregiver. Where there was more than one caregiver per participant, a single key informant was recruited, even though the total number of caregivers per patient were noted.

Inclusion Criteria (for patients with schizophrenia)

In-patients/out-patient diagnosed with Schizophrenia; Age 15 years and above

Exclusion Criteria (for patients with schizophrenia)

Patients with history of stroke, head injury, Intellectual Disability or Delirium despite previous diagnosis of schizophrenia; Patients less than 18 years and not accompanied by a caregiver.

Inclusion Criteria (for caregivers)

Age 18 years and above.

Exclusion Criteria (for caregivers)

Caregiver(s) who are acutely ill; Caregiver(s) with a medical disorder; Caregivers who declined consent.

Study Design

This was a longitudinal comparative study.

Instruments used in this Study

Socio-demographic questionnaire

This was designed to obtain socio-demographic information such as age, sex, occupation, marital status, level of education, socioeconomic status (SES). There is no consensus on the conceptual meaning and measurement of SES. For the purpose of this study a modification of Kuppaswamy SES Scale as revised by Guru Raj *et al.*¹¹ was adapted for use. This took cognizance of the educational level of participants, the occupational status, income, place of residence, number of dependents and ownership of property of value. The SES was then classified into high, middle, and low socioeconomic class based on the total score obtained thus: a score of 26–29 = upper class; 11–25 = middle class; <15 = lower class. At the time of this study the US\$ = N190; The minimum wage was N18,000.

A modified structured COI questionnaire, adapted from the Centers for Disease Control and Prevention (CDC), U.S. Department of Health & Human Services,³ was used to assess direct cost (e.g. cost of treatments, transportation, feeding, investigations, etc.) for patient and care-giver.

Zarit Burden Interview (ZBI):¹²

Originally designed to reflect the stresses experienced by caregivers of dementia patients, its use has been extended to relatives of patients with chronic mental and medical illnesses. The full revised

version (with 22 items) by Zarit *et al.*¹³ has a score ranging from 0-88, depending on the caregiver response. Responses are rated from 0 to 4 based on the degree of distress, with scores ranging from 0 to 1 regarded as negative while scores ranging from 2 to 4 as positive scores. The ZBI has excellent internal consistency ($\alpha = 0.83$ and 0.89) in two different studies,^{12,13} and has the advantage that results obtained across studies can easily be compared. The instrument has been validated in Nigeria and a Hausa version by Yusuf *et al.*⁶ was administered to participants who did not understand English language.

The Positive and Negative Syndrome Scale (PANSS) was developed by Kay *et al.*¹⁴ to remedy perceived deficits in the Brief Psychiatric Rating Scale (from where it was adapted) in the assessment of positive and negative symptoms of schizophrenia and other psychotic disorders. It is a 30 items scale on three subscales: seven items covering positive symptoms, seven covering negative symptoms, and 16 covering general psychopathology. Each item is scored on a seven-point, item-specific Likert scale ranging from 1 to 7. The PANSS requires a trained professional to administer can be completed in 30 to 50 minutes. Reliability for each scale has been shown to be fairly high, with excellent internal consistency and inter-rater reliability.¹⁴

The Mini International Neuropsychiatric Interview (MINI) PLUS¹⁵ is a more detailed edition of the MINI. The MINI was designed as a brief structured interview for the major Axis I psychiatric disorders in the ICD-10¹⁶ and DSM-IV.¹⁷ It requires Yes or No answers. Validity and Reliability studies has shown the MINI to have high validity and reliability scores but can be administered in a much shorter period of time (mean time 18.7 ± 11.6). The instrument requires brief training for clinicians but more extensive training for lay interviewers. The instrument has been used in studies in Nigeria by Adewuya *et al.*¹⁸ The

MINI PLUS was administered to patients, portions related to schizophrenia and to the caregivers, sections related to mood and anxiety disorders. Patients' case files were also assessed for other information such as their other medical history, type of investigations carried out, treatment being given etc

.Sample Size Determination

This was calculated using the formula for comparison of two means:¹⁹
$$n = \frac{(u+v)^2(a_i^2 + a_0^2)}{(u_1 - u_0)^2}$$

(Where the aim is to demonstrate a significant difference between cost of treatment for stable and acute patients with schizophrenia); Where: n = required minimum sample size of each group: 90 for acute patient and 180 for stable patients with schizophrenia

Cost Estimation

The costs of registration, admissions and consultations were obtained from the Records Departments while costs of drugs were obtained from the hospital pharmacy. The costs of investigations were obtained from the various laboratories. The cost of transportation was obtained from the various transport stations, and motor parks. The daily cost of feeding was got from the nutrition and catering services department

Ethical Consideration

Ethical clearance was obtained from the Ethics and Scientific Committee of the Ahmadu Bello University Teaching Hospital. A written and signed consent, was obtained from participants before conducting the interview. For patients less than 18 years, consent was obtained from their caregiver. Patients and their caregivers were given due priority in terms of prompt management in the wards and at the clinics in view of the length of the interview per participant

.Diagnosis

The diagnoses of schizophrenia, depression and anxiety disorder were based on fulfilling the criteria in the WHO's Tenth Revision of the International Classification of Disease and Related Health Problems, (ICD-10)¹⁶ as assessed using the MINI PLUS

Data Analysis

The data was analyzed using the version 20 of the Statistical Package for Social Sciences (SPSS). Relevant descriptive statistics were used for continuous and categorical variables and frequency distributions generated. Test of normality for all continuous variables were assessed using the Kolmogorov-Smirnoff test. The non-parametric equivalents of the corresponding relevant test statistic were then employed. These included the Mann-Whitney U test, Kruskal-Wallis test, and Spearman's correlation. Regression analysis was also employed to determine the predictors of cost. All tests of statistics were carried out at 5% level of probability. A prevalence based approach was adopted whereby all costs within the most recent year for which data were available, were measured regardless of date of onset of illness.

RESULTS

Socio-demographic Characteristics of the Participants (Table 1). A total of 270 subjects participated in this study with two thirds (66.7%) of them receiving acute phase treatment. All patients consented to participate in the study. The sex ratio was approximately 1:1 with 48.1% of the participants being males. The mean age was 33.04 (±9.743), however mean age at onset of illness was 25.87 (±8.139). The age for all the patients ranged from 15 to 60 years. Most of the participants 123(45.6%) were single with most of these singles being males 96(78.05%). Most of the subjects 239(88.5%) were of low SES. Majority were unemployed 138(51.1%)

while 33(12.2%) were students. Islam was the predominant religion 229(84.8%). Only 28(10.37%) of the participants were benefitting from the National Health Insurance Scheme (NHIS), most 25(98.93%) of whom were either staff or students of the tertiary institution, Ahmadu Bello University Zaria. Pertaining the caregiver, 165(61.1%) of the patients were accompanied by at least one caregiver

Socio-demographic characteristics of Caregivers

All the participants receiving acute phase treatment had at least one caregiver, while less than half (41.7%) of the stable patients were accompanied by a caregiver.

Table 1: Socio-demographic Characteristics of Participants with Schizophrenia (N=270)

Variables	Freq.	%
Presentation:		
Acute	90	33.3
Stable	180	66.7
Sex:		
Male	130	48.1
Female	140	51.9
Age(years):		
15-24	51	18.9
25-34	109	40.4
35-44	74	27.4
45-54	28	10.3
55-64	8	3.0
M/Status:		
Single	123	45.6
Married	93	34.4
Divorced	38	14.1
Separated	6	2.2
Widowed	10	3.7
Occupation:		
Employed	99	36.7
Unemployed	138	51.1
Student	33	12.2
Education:		
None	44	16.3
Primary	80	29.6
Secondary	78	28.9
Tertiary	68	25.2
SES		
Low	239	88.5
Middle	24	8.9
High	7	2.6
Religion:		

SES: Socio-economic status %: Percentage Freq:Frequency

Table 2: Relationship between Socio-Demographic Variables of Patients with Schizophrenia and Caregivers Burden

VARIABLES	BURDEN (N)		STATISTICS
	Mild/Mod	Mod/Sev	
Presentation:			
Acute	33	57	X ² =22.098 df=1; p<0.001**
Stable	55	20	
Sex:			
Male	50	39	X ² = 0.629 df=1; p=0.428
Female	38	38	
M/Status:			
Single	44	34	X ² = 5.534 df = 4 p = 0.237
Married	29	22	
Divorced	10	14	
Separated	1	5	
Widowed	4	1	
SFS:			
Low	80	71	X ² =0.115 df= 2 p=0.944
Middle	5	4	
High	3	2	
Educ Level:			
None	17	14	X ² = 3.224 df = 3 p = 0.358
1 ^o	25	31	
2 ^o	25	20	
3 ^o	21	17	
Occup. Status:			
Unemployed	43	49	X ² =3.636 df= 2 P = 0.162
Employed	34	21	
Student	11	7	
Religion:			
Christianity	13	14	X ² = 0.349 df=1; p=0.555
Islam	75	63	
NHIS Registered			
Yes	7	6	X ² =1.061 df=1; p=0.588
No	81	71	

Significant at 0.01 level

Interpretation of Zarit Score:

A. 0 - 20 little or no burden

B. 21 - 40 mild to moderate burden

C. 41 - 60 moderate to severe burden

D. 61 - 88 severe burden

NB: A and B were merged (due to some empty cells in group A).

No participant fell in group D.

Female caregivers predominated in this study 86(52.12%). Most of the caregivers were parents (52.73%), followed by siblings (20.61%). Caregivers with no educational attainment constitute the majority 62(37.58%) and those with primary education the least 27(16.36%). Caregivers with anxiety disorder constituted 21.8% of all caregivers, while (18)10.9% had a diagnosis of depression. Those with no diagnosis made up 67.27% Zarit

Table 3: Correlates of Zarit Burden Score

Variables	Zarit Burden Score	
	R	p-value
No. of Caregiver	0.302	<0.001**
Length of Caregiving	0.578	<0.001**
DUP	0.163	0.037*
COI	0.328	<0.001**
PANSS:		
Positive Subscale	0.636	<0.001
Negative Subscale	0.346	<0.001
General Subscale	0.519	<0.001
Total	0.558	<0.001

Significant at 0.01 level

Significant at 0.05 level

r: Spearman's Correlation

DUP: Duration of Untreated Psychosis

COI: Cost of Illness

PANSS: Positive and Negative Syndrome Scale

Table 4: Multiple Regression Model: Predictors of Total Direct Cost^a

Independent Variables	Coefficients		t	p - value
	Unstandardized	Standardized		
	B	Beta		
Zarit Burden Score	-105.89	0.049	0.549	0.584
PANSS Total Score	-43.50	-0.040	-0.427	0.674
Age	1.514	0.001	0.214	0.831
Number of Caregivers	4261.5	0.130	1.741	0.084
Length of caregiving	3662.7	0.383	4.135	0.000
Socioeconomic status	10043.8	0.191	2.738	0.007

^aR Square = 0.294; Adjusted R Square = 0.267; p<0.001; n = 165

Dependent Variable = Total cost

Burden Score and Caregiver Burden. Up to half of the caregivers 83(50.3%) had mild to moderate levels of burden, with 77(46.7%) having moderate to severe burden. Relationship between Socio-Demographic Variables of Patients with Schizophrenia and Caregivers Burden (Table 2). It showed a statistically significant relationship between burden of care and presentation of participants ($\chi^2=22.098$, $df=1$, $p<0.001$).

There was however, no relationship between burden of care with sex ($p=0.428$), marital status ($p = 0.237$), SES ($p=0.944$), educational level ($p = 0.358$), and religion ($p = 0.555$) Correlations of Zarit Burden Score (Table 3): The relationship was statistically significant between the Zarit Burden Score and the

Number of Caregiver per participant ($p < 0.001$), length of caregiving ($p < 0.001$), and Cost of illness ($p < 0.001$). The relationship was also statistically significant between the Zarit Burden Score and DUP (0.05 level of significance). The relationship with duration of Illness (DOI) however failed to reach statistical significance ($p = 0.965$)

DISCUSSION

Socio-demographic Characteristics of Participants

A total of 270 subjects participated in this study comprising stable schizophrenia patients receiving maintenance therapy and schizophrenia patients receiving acute phase treatment in the ratio 2:1. The male to female ratio was 0.9:1. Several community and hospital based studies have shown an almost 1:1 male: female ratio in the prevalence of schizophrenia.^{5,10} This is because the incidence and prevalence of schizophrenia in both males and females is approximately the same even though the mean age of onset is earlier in males. The mean age of participants is 33.04 (SD \pm 9.743). This reflects the fact that schizophrenia can occur in the young (as early as ten years) as well as middle age and similar to the findings by Oloninyi *et al.*^{9,10} This can also be attributed to the findings that patients with schizophrenia in most developing countries frequently present with long duration of untreated illness, largely due to the long pathway to care.²⁰ Some of the participants have been in treatment over a long period due to the chronic nature of schizophrenia and the ages recorded were the ages at the time of the study in contrast to the age at the onset of the illness. Most of the participants were unemployed. The occurrence of schizophrenia during adolescence and early adulthood means that the attainment of academic and occupational skills is truncated. Both the positive and negative symptoms as well as the cognitive deficits associated with the

illness contributes immensely to the difficulties encountered in trying to achieve academic prowess and vocational competence.^{5,10,21} Most of the study participants were of low SES. Several studies have found an overrepresentation of schizophrenia patients in the low socioeconomic class.^{5,10} The implication however is that, continuous use of medication is jeopardized and use of newer antipsychotics for patients less tolerant to conventional antipsychotics is restricted.

Socio-demographic Characteristics of Caregivers

Several studies (especially those from developing countries) have been consistent in their finding of an overrepresentation of female caregivers for patients with schizophrenia.^{6,7,9} Females are traditional caregivers in many African settings whereas the males predominate as the breadwinners and are more frequently employed. Majority of the caregivers were parents of the patients 87(52.73%). Studies have shown that majority of patients (40-90%) live with their families particularly in developing countries where the extended family system of living is still common. Though this has the advantage of sharing the burden of care among family members, it may however increase the indirect cost of treatment due to loss of productive time.^{1,2,4,6,9,10} This study found a statistically significant relationship between burden of care and illness presentation. Patients presenting with acute symptoms frequently constitute significant source of stress for their caregivers.⁹ Caregivers of acutely ill patients are frequently kept on their feet providing care, preventing them from harming themselves or others and attending to the financial demands of hospital care. This is in addition to the social stigma caregivers contend with. Other studies have shown similarly that the leading determinants of burden rest with symptoms of patients and the associated social stigma.^{2,6,7} Burden of care still occurs irrespective of socio-demographic attribute of the patients and their caregivers such as

level of education and SES.

Relationship between Caregiver Burden and COI

The relationship between number of caregivers and COI consistently showed statistical significance even after controlling for participants' presentation ($p < 0.001$). The number of caregivers is frequently a reflection of the severity of symptoms and the need for ongoing care. Within hospital settings, it reflects the need for higher doses of medication and possible sedation, the possible need for ECT, closer monitoring and psychotherapy for both patient and their caregivers. Studies have shown that the number of caregivers per patient influence the cost of treatment especially the indirect cost due to the effect of lost productivity.^{22,23}

Correlates of Zarit Burden Score among Caregivers

This study revealed a statistically significant relationship between the Zarit score and the number of caregivers ($p < 0.001$), length of caregiving ($p < 0.001$), Cost of illness ($p < 0.001$) and all the PANSS subscales ($p < 0.001$). The number of caregivers and length of caregiving per patient is a reflection of the severity of symptoms and the need for care. These constitute sources of burden for the caregiver as shown by other previous studies.^{6,7} Cost on the other hand constitute source of financial drain on caregivers and invariably, a sources of burden. The Zarit Burden Score measures the level of burden resulting from caregiving and is found to have a significant positive correlation with symptoms' profile. The studies by Yusuf *et al.*⁶ and Igberase *et al.*⁷ have also shown that patients' symptoms are a major source of burden on care givers as reflected in the significant positive correlation between length of caregiving and number of caregivers with all the subscales of PANSS in this study.

CONCLUSION

The conclusions drawn from this study are cause for concern. The difference between the direct cost of treatment of patients with acute schizophrenia and stable patients is statistically significant and emphasizes the need for efforts that will be geared towards drug adherence and relapse prevention such as effort on stigma reduction, community care and rehabilitation programs. The socio-demographic factors associated with direct cost of schizophrenia include SES, and mode of presentation. The length of caregiving, and SES were significant predictor of direct cost of treatment. The factors associated with caregiver burden included patients' presentation, and symptom profile which further reiterates the importance of relapse prevention strategies.

Recommendations

The complications of schizophrenia are multifaceted. The modest estimate found in this study does not put into consideration the cost of rehabilitation programs for persons with treatment resistance, persistent residual symptoms, continuing cognitive deficits, and poor socioeconomic functioning. The inclusion of these variables will give a better picture of the enormity of the economic burden to the nation.

Limitation

This study is not without limitations. There are no formal standardized cost estimates particularly for services that have been subsidized or taken up by government to make references to, and enhance standardization. Also, the absence of social services, rehabilitation and long stay homes makes the real cost estimation incomplete

Conflict of Interest

We declare that we have no conflict of interest.

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