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PRIMARY CAREGIVERS OF THE MENTALLY ILL EXPERIENCE MORE BURDEN: A COMPARATIVE STUDY OF MENTAL VERSUS PHYSICAL ILLNESS

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ABSTRACT

Background: **Caring for patients with chronic illnesses whether mental or physical imposes a burden on caregivers. Schizophrenia and Type 2 Diabetes Mellitus (DM) are both chronic illnesses which require long term care, though they differ in pathophysiologic concepts. Planning strategies for improving the quality of life of caregivers of these patients will require that clinicians answer the pertinent question of who experiences more burden.**

Objective: **This study assessed and compared the burden of care in caregivers of patients with schizophrenia and Type 2 DM, determined caregiver and patient characteristics that predict burden in both groups.**

Design: **Cross-sectional study.**

Setting: **Endocrinology and Psychiatry outpatient clinics of the University of Ilorin Teaching Hospital, Ilorin, Nigeria.**

Participants: **One hundred patients with schizophrenia and 100 patients with Type 2 DM, along with their primary caregivers.**

Outcome measures: **Caregiver burden was assessed using the ZBI.**

Results: **Caregivers of schizophrenia patients experienced significantly higher burden than caregivers of Type 2 DM (p=0.025). Predictors of burden in**

schizophrenia patients' caregivers were caregiver age (OR=2.088), being a lone caregiver (OR=1.39), perceiving caregiving as problematic (OR=6.194), GHQ-12 scores of caregiver (OR=7.46) as well as the presence of psychopathology (OR=2.61). The predictors of burden in Type 2 DM patients' caregivers were caregiver gender (OR=4.049) presence of physical complications (OR=1.547).

Conclusion: **Caregivers of patients with schizophrenia were found to experience significantly higher levels of burden and psychological distress and this is important in planning care strategies for this group of patients.**

INTRODUCTION

A caregiver is an individual who has the responsibility of meeting the physical, psychological, spiritual and financial needs of a dependent patient and is saddled with the responsibility of performing caregiving duties. (1,2). The burden of the caregiver describes a psychological state that results from the combination of physical and emotional work, as well as social pressure and economic restrictions that arise from taking care of patients. (3) It can be objective or subjective. (4,5).

Schizophrenia is a chronic mental disorder with devastating effects on both patient and caregivers. The burden of care imposed on caregivers has been found to be associated directly with the presence of florid positive and negative symptoms of schizophrenia in the patient. (6) Type 2 Diabetes mellitus (Type 2 DM), in the same vein is a chronic medical illness that places serious constraints on the patient's activities (7,8) and requires significant behavioral change in the family members and caregivers of such patients. This may lead to psychosocial conflicts in the patient and caregivers especially those in the family environment.

Although several studies in different parts of the world have examined caregiver burden and quality of life of caregivers of patients with chronic mental and physical illnesses independently there is paucity of studies comparing the two to answer the pertinent question of which group of caregivers experience more burden. This study therefore assessed and compared the caregiver burden and associated factors in caregivers of schizophrenic patients with that of Type 2 DM patients (as examples of a chronic mental and a chronic physical illness), with a view of recommending strategies to mitigate this burden.

Aim and objectives: To assess and compare the burden of care among caregivers of patients with Schizophrenia and Type 2 DM and to determine patient and caregiver factors that are associated with burden in each group.

MATERIALS AND METHODS

Study design: Cross sectional study conducted between June and December 2016.

*Study setting: T*he Psychiatry and Endocrinology outpatient clinics of the University of Ilorin Teaching Hospital (UITH), Ilorin, Kwara State.

Sample size determination: The Fleiss formula (9) for comparative studies with the power set at 95%, giving a sample size of 100, after correcting for attrition.

Study participants: 100 patients with schizophrenia and their primary caregivers as well as one hundred patients with Type 2 DM and their primary caregivers were recruited via systematic random sampling technique, selecting every fourth patient-caregiver dyad who met the inclusion criteria.

Data collection: Four data collection tools were used- socio-demographic questionnaire with questions on the biodata of the patient and caregiver and relevant patient and caregiver related factors relevant to caregiver burden.

Patients were first interviewed using a socio-demographic questionnaire designed and pretested by the researcher. The Mini International Neuropsychiatric Interview (M.I.N.I.) was used to confirm the diagnosis of schizophrenia, assess the presence of psychopathology in patients with schizophrenia and was also used to screen Type 2 DM patients for symptoms of schizophrenia. The patients with schizophrenia were further screened for Type 2 DM using Random Blood Sugar (RBS). Patients with values ≥ 11.1 mmol/L were excluded. All caregivers were interviewed with a socio-demographic questionnaire, the 12-item General Health Questionnaire (GHQ-12) and the care burden was measured using the Zarit Burden Interview (ZBI). A total score of 0 to 20 indicates none to mild burden, 21 to 40 indicates mild to moderate burden, 41 to 60 indicates moderate to severe burden, while 61-80 indicates severe burden. (10) In this study, the ZBI scores were dichotomized into the high and low burden groups, with a score of 0-40 denoting low burden of care, and 41-88 denoting high burden according to previously established norms from earlier studies. (11,12)

Caregivers and patients were interviewed separately to ensure confidentiality. All questionnaires were back translated by bilingual experts into Yoruba, the predominant language spoken in the study area, for study participants who do not understand English

Inclusion and exclusion criteria for patients:

Type 2 DM Group: Adult Type 2 DM patients aged 18 to 65years diagnosed according to the WHO criteria (13) who had had the illness for six months and above were included in the study, while those who were too ill to participate in the study were excluded.

Schizophrenia Group: Adult patients with schizophrenia, who were diagnosed using the ICD-10 diagnosis and who were aged 18 to 65 years, with illness duration of six months and above were included in the study, while schizophrenia patients who were diagnosed as been diabetic were excluded from the study.

Inclusion and Exclusion criteria for caregivers: Caregivers who were aged 18 to 65 years and had been taking care of the patient for six months or more were included in the study for both groups, while caregivers with a current or past history of mental illness were excluded from the study.

Data analysis: The Data generated from this study was analyzed using the Statistical Package for Social Sciences (SPSS version 20). Descriptive statistics were used to summarize the data. Continuous variables were expressed as mean ± standard deviation, while frequencies of categorical variables were expressed as percentages. The chi square was used to analyze categorical and continuous variables. Logistic regression was then used to identify predictors of burden of care. The significance level was set at $p<0.05$.

Ethical considerations: An Ethical approval for the study was obtained from the Ethics and Research Committee of the University of Ilorin Teaching Hospital. (Approval code: ERC PAN/2015/0571416) and the research was done according to the principles of the Helsinki declaration.

RESULTS

Socio-demographic variables

The mean age of caregivers of patients with schizophrenia was 48.74 ±13.44 years, while the mean age of caregivers of patients with Type 2 DM was 46.46 ±14.48. The difference between the mean ages of caregivers in both groups was not statistically significant. (t=1.154, p=0.25). Forty-four (44%) caregivers were males in each of both groups, while 56 (56%) were females in each of both groups, as caregivers in both groups were matched for gender. Majority of caregivers of both groups of patients were married. There was no significant difference in the marital status of both groups of caregivers. (p = 0.448). Majority of caregivers were of Yoruba Ethnicity. (Table 1)

Table 1

Socio-demographic characteristics of caregivers of patients with schizophrenia and type 2 diabetes mellitus

	Type of caregiver			
Variables	Schizophrenia	Diabetes	χ^2	*p* value
	n (%)	n (%)		
Age group				
≤ 20	3 (3.0)	6 (6.0)	1.039^{Y}	0.792
21 – 40	22 (22.0)	27 (27.0)		
41 – 60	57 (57.0)	52 (52.0)		
> 60	18 (18.0)	15 (15.0)		
Mean Age ± SD	48.74 ± 13.44	46.46 ± 14.48	t=1.154	0.250
Gender				
Male	44 (44.0)	44(44.0)	0.000	1.000
Female	56 (56.0)	56 (56.0)		
Marital status				
Single	14 (14.0)	21 (21.0)	2.654^{Y}	0.448
Married	78 (78.0)	77 (77.0)		
Divorced/Separated/ Widowed	8(8.0)	2 (2.0)		
Ethnicity				
Yoruba	88 (88.0)	87 (87)	0.225^{Y}	0.973
Hausa	5 (5.0)	5 (5.0)		
Igbo	3 (3.0)	5 (5.0)		
Others	4 (4.0)	3 (3.0)		
Religion				
Christianity	41 (41.0)	51 (51.0)	2.013	0.156
Islam	59 (59.0)	49 (49.0)		
Educational qualification				
No formal	19 (19.0)	5 (5.0)	16.768	0.001*
Primary	17 (17.0)	10 (10.0)		
Secondary	22 (22.0)	17 (17.0)		
Tertiary	42 (42.0)	68 (68.0)		
Employment status				
Employed	81 (81.0)	66 (66.0)	5.776	0.016*

Unemployed	19(19.0)	34(34.0)		
Relationship to patient				
Parents	37 (37.0)	10 (10.0)	41.012	0.001*
Child	11 (11.0)	40 (40.0)		
Spouse	20 (20.0)	34 (34.0)		
Siblings	21 (21.0)	11 (11.0)		
Others /Unrelated	11(11.0)	5(5.0)		

*χ^2: Chi square test; df: degree of freedom; Y: Yates corrected chi square; t- T test, *: p value <0.05*

Comparison of caregiving characteristics

The mean length in years of caregiving for caregivers of patients with schizophrenia was 7.99±7.62, while that of caregivers in the Type 2 DM group was 6.67± 5.80.(p= 0.189). More than half of caregivers of patients in both groups had been taking care of the patients for ≤ 5years. The difference was not statistically significant(p=0.197). More caregivers of patients with schizophrenia were the only ones taking care of the patient than caregivers in the Type 2 DM group. The difference in the two groups in terms of being the only caregiver was statistically significant (p= 0.020). (Table 2)

Table 2

Comparison of caregiving characteristics of caregivers of patients with schizophrenia and type 2 diabetes mellitus

	Type of caregiver			
	Schizophrenia	Type 2 DM	χ^2	*p* value
Variable	n (%)	n (%)		
Duration of Caregiving				
< 5 years	53 (53.0)	60 (60.0)	3.249	0.197
6 – 10 years	23 (23.0)	26 (26.0)		
> 10 years	24 (24.0)	14 (14.0)		
Mean (SD)	7.99±7.62	6.6±5.80)	1.318	0.189
Lone caregiver				
Yes	37 (37.0)	22 (22.0)	5.409	0.020*
No	63 (63.0)	78 (78.0)		
Paid for caregiving				
Yes	2 (2.0)	1 (1.0)	0.000^{Y}	1.000
No	98 (98.0)	99 (99.0)		
Residing with patient				
Yes	77 (77.0)	67 (67.0)	2.480	0.115
No	23 (23.0)	33 (33.0)		
Frequency of contact with patient				
Daily	81 (81.0)	83 (83.9)	0.389^{Y}	0.942
Weekly	10 (10.0)	10 (10.0)		
2 to 3 times a month/	9 (9.0)	7 (7.0)		
Several times a year				
Number of hours of contact with patient				
≤ 5 hours	8 (9.9)	12 (14.5)	2.360	0.501

6-10 hours	17 (21.0)	18 (21.7)		
11-15 hours	17 (21.0)	22 (26.5)		
>16hours	39 (48.1)	31 (37.3)		
Distance to Hospital (km)				
≤ 5	5 (5.0)	4 (4.0)	0.966	0.810
6 – 10	5 (5.0)	6 (6.0)		
11 – 15	19 (19.0)	24 (24.0)		
> 15	71 (71.0)	66 (66.0)		

*χ^2: Chi square test; df: degree of freedom; Y: Yates corrected chi square; *: p value <0.05*

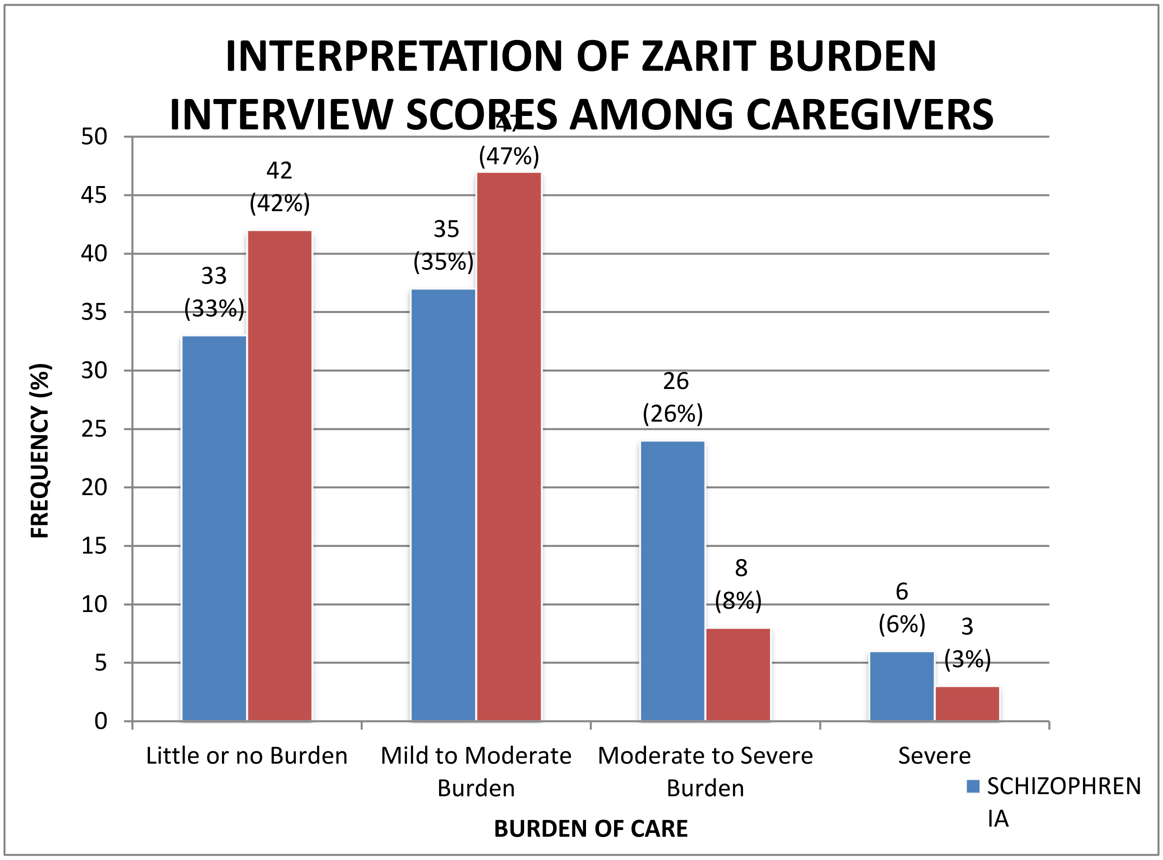

Figure 1: Bar chart showing burden of care among caregivers of patients with Schizophrenia and Type 2 Diabetes mellitus

Caregiver and patient factors associated with burden

In caregivers of patients with schizophrenia, caregiver burden was significantly associated with the following caregiver factors: the age of caregiver (p=0.019), marital status of the caregiver (p=0.044), (Table 4)being a lone caregiver (p=0.006), caregiver's perception of caregiving as being beneficial (p=0.048), caregiving perceived as problematic(p<0.001) caregiver GHQ scores (p<0.001) as well as being responsible for financing patient's treatment (p = 0.026). Patient factors significantly associated with burden were presence of psychopathology as assessed by the M.I.N.I. (p=0.004).

In caregivers of patients with Type 2 DM, caregiver burden was significantly related to the gender of the caregiver (p=0.005) and the presence of physical complications in patients (p < 0.001).

Predictors of burden of care among caregivers of patients with schizophrenia and diabetes mellitus

A binary logistic regression was performed to ascertain the independent predictors of high burden among the caregivers of schizophrenia patients (Table 3). The dichotomized outcomes were defined as "low burden of care" (ZBI score ≤ 40) and "high burden of care" (ZBI score >41). The variables that showed a significant association with burden of care were imputed in to the regression model.

The results indicated that an increase in the age of caregiver by one year increased the odds of having a high burden of care by about two times (OR=2.088). Those who were lone caregivers were about one and a half times more likely to experience a high burden of care compared with those who shared caregiving duties (OR=1.391). The caregivers who perceived that the caregiving role was problematic for them were about six times more likely to report a high burden of care compared to those who did not (OR= 6.194). Caregivers with GHQ-12 scores ≥ 3 were about seven and a half times more likely to report a high burden of care compared with those with GHQ-12 scores <3 (OR=7.469). Among caregivers whose patients with Type 2 DM, the results indicate that female caregivers had a four-fold likelihood of reporting a high burden of care compared to male caregivers (OR=4.049) and caregivers of Type 2 DM patients who had complications of disease were about one and a half times more likely to report a high burden of care compared with caregivers whose patients had no physical complications (OR=1.547).

For the diabetes group (Table 4), The results indicate that female caregivers had a four-fold likelihood of reporting a high burden of care compared to male caregivers (OR=4.049) and caregivers of Type 2 DM patients who had complications of disease were about one and a half times more likely to report a high burden of care compared with caregivers whose patients had no physical complications (OR=1.547).

Table 4

Predictors of burden of care in caregivers of patients with schizophrenia

Variable	B	*p* value	OR	95% CI	
				Lower	Upper
Age of caregiver (years)	0.093	0.033*	2.088	1.007	4.196
Lone Caregiver (No- Ref, Yes- 1)	0.330	0.048*	1.391	1.023	4.574
Caregiving Role perceived as problematic (No-Ref, Yes- 1)	1.824	0.007*	6.194	1.634	23.486
GHQ-12score (GHQ Score <3- Ref, GHQ Score 0≥ 3- 1)	2.011	0.001*	7.469	2.179	25.594
M.I.N.I. diagnosis of patient (Lifetime Psychotic syndrome- Ref, Current Psychotic Syndrome- 1)	0.958	0.012*	2.607	1.776	8.985

B: Regression coefficient, OR- Odds Ratio, CI- Confidence Interval, GHQ- General Health Questionnaire-12 score, M.I.N.I. – Mini International Neuropsychiatric Interview, 0-Reference Group

Table 5

Predictors of burden of care in caregivers of type 2 diabetes mellitus

Variable	**B**	***p* value**	**OR**	**95% CI**	
				Lower	Upper
Gender of the caregiver (Male- Ref, Female- 1)	1.398	0.005*	4.049	1.533	10.693
Presence of Physical complications in patient (No physical complication- Ref, Presence of physical complications- 1)	0.436	0.039*	1.547	1.176	4.158
GHQ-12 Score (GHQ Score <3- Ref, GHQ Score ≥ 3- 1)	-0.691	0.152	0.501	0.195	1.288

*B: Regression coefficient, OR- Odds Ratio, Sex: Male- 0, Female- 1, Presence of physical complications- No physical complication- 0, Presence of physical complications- 1, GHQ-12 Score: GHQ Score <3- 0, GHQ Score ≥ 3- 1. *p<0.05*

DISCUSSION

The two groups of caregivers in this study were similar in most of their socio-demographic characteristics and the mean age of the caregivers of schizophrenia patients (41-60 years) was similar to the mean age of caregivers reported in similar studies (14,15)

In this study, majority of caregivers in both groups were females. This finding is in agreement with previous studies in Nigeria and other parts of the world that reported that females constitute the greater population amongst caregivers of patients with chronic mental or physical illnesses. (16,17) This may be linked to the fact that culturally, females are usually expected to naturally take on the duties of caregiving, as most caregiving duties are considered as feminine tasks. We also found that the mean burden score in caregivers of patients with schizophrenia was significantly higher than that of caregivers of Type 2 DM patients. In addition, significantly higher proportion of caregivers in the schizophrenia group had moderate to severe and severe burden than those in the Type 2 DM group. This finding suggests that it is more burdensome to care for a patient with a chronic mental illness such as schizophrenia, than a patient with a chronic medical illness such as Type 2 DM. This is in keeping with findings by Lasebikan and Ayinde in Nigeria who compared burden in chronic mental and physical illness. (18)

This trend may be attributable to the fact that caregivers of patient with schizophrenia may be faced with more difficulties associated with caregiving such as managing psychotic symptoms, which may most times be frightening and embarrassing to the caregiver. Such experiences, coupled with the associated stigmatization of the mentally ill and their relatives in this environment, may make caregiving an uphill task. (19)

The predictors of caregiver burden identified in schizophrenia were the age of the caregiver, being a lone caregiver, a perception of caregiving as being problematic, the presence of psychological distress (as measured by the GHQ-12) and the presence of psychopathology Some of the predictors found were in keeping with that found in previous studies. Jagannathan et al (20) in their study of the predictors of burden in schizophrenia in India identified the presence of psychopathology as a predictor of burden. This was also reported in studies by Upkong (10) and Dyek et al (21) who found the presence of psychotic symptoms as a predictor of burden. These findings suggest that the presence of psychopathology in a patient with schizophrenia may increase the need for supervision of the patient, lead to more dysfunction in the patient's life and thus, increase the burden of responsibilities and the need for assistance by the caregiver.

Being the only caregiver of a patient with schizophrenia was found to be a predictor of burden in this study. This finding may be linked to the fact that an only caregiver has to shoulder all the caregiving responsibilities without the support of others, thereby experiencing immense burden. This is especially relevant in a country like Nigeria, where there are no fully established social welfare programs and treatment costs are borne by the patients and their caregivers. Also, the presence of psychological distress as a predictor of burden in schizophrenia has been reported by many previous similar studies in this environment. (4,14)

On the other hand, in the Type 2 DM group, only two factors were found to be predictors of burden in caregivers in this group. These were the gender of the caregiver and the presence of complications of the disease. Although there is paucity of studies regarding the predictors of burden in Type 2 DM, the presence of complications of the illness has been consistently reported by some researchers as being strongly associated with the burden of care. Langa et al(22) reported that as the number of complications of DM increase, the complexity of care and the need for medication-related help increases, leading to more burden on the caregiver.

CONCLUSION

This study shows that caregivers of patients with a mental illness such as schizophrenia are significantly more burdened than those taking care of patients with chronic illnesses such as

Type 2 DM. Several caregiver and patient related factors have been found to be associated with this. Therefore, clinicians should take particular care in addressing such factors in order to reduce burden and promote a better quality of life in caregivers as this may impact on the outcome of treatment of these patients.

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