# Burden and Psychological Distress Among Nigerian Family Caregivers of Schizophrenic Patients: The Role of Positive and Negative Symptoms

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**SUMMARY**

**Objective:** To determine the relationship between symptoms of schizophrenia and caregiver burden/distress among caregivers of people with schizophrenia in southwestern Nigeria.

**Method:** One hundred and one family caregivers of 101 patients with schizophrenia were recruited into the study. Caregivers were screened with the Zarit Burden Interview (ZBI) to measure caregiver burden and the 30 item General Health Questionnaire (GHQ-30) to measure psychological distress. Patients were interviewed using the Brief Psychiatric Rating Scale (BPRS) and the Scale for the Assessment of Negative Symptoms (SANS) to rate psychopathology.

**Results:** More than half of the caregivers were females (58.4%). About one third of caregivers (33.7%) were experiencing moderate/severe levels of burden even though the mean burden score of 32.6± 14.1 for the sample was in the mild/moderate range on the ZBI scale. Using regression analysis, it was found that higher caregiver burden scores were associated with negative symptoms of asociality-anhedonia, whereas high GHQ-30 scores were associated with inattention and avolition. High caregiver burden scores were also associated the patient being unemployed and the caregiver having lower education, whereas high levels of emotional distress in the caregiver was related to the patient being female and the patient having a lower education level.

**Conclusions:** These results underscore the need for continued intervention for family members of Schizophrenic patients. Part of the care plan for the caregiver should include education on the negative symptoms of the illness.

**Key Words:** Positive symptoms, Negative symptoms, caregiver burden, schizophrenia.

## INTRODUCTION

The consequences of schizophrenia extend beyond the ill individual to the family, as relatives are often the caregivers for the patient (Zahid and Ohaeri ,2010; Sefasi et al.,2007; Perlick et al.,2006; Provencher & Mueser, 1997; Charkarbarti & Kulhara, 1999; Bellack et al., 1990; Creer & Wing 1975). The prevalence of schizophrenia is similar in developed and developing nations, and environment is known to play a crucial role in patient prognosis. Supportive family attitudes and extended family networks have been described as a possibleexplanation for this observation (Jablensky A, 1995; Leff 1992), however, caregiver burden in psychiatric illness is enormous and continues to be a focus of research in developed countries, where community participation in the care of the mentally ill is prioritized. More than 60% of individuals who experience their first episode of a major mental disorder return home to live with relatives and thus it is important to evaluate the impact of problem behaviors on caregiver burden/distress levels in order to better understand which factors produce the most stress for caregivers (Provencher and Mueser, 1997; Macmillan et al 1986).

Nigeria is a developing country with a population of over 150 million, and schizophrenia accounts for about 55% of all in-patient psychiatric admissions in the country (Ukpong & Mosaku ,2008). Even though Nigeria is endowed with rich

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cultural resources like the extended family system, the cohesiveness of this family-based social support structure is on the decline, with a shift towards nuclear family units more characteristic of westernized nations.

Despite this trend, the family of the Nigerian psychiatric patient continues to play a very crucial role in the management of a mentally ill relative, and thus there is a need to examine how positive and negative symptom behaviors in schizophrenic patients affect caregiver burden/distress levels, with the long-term goal of improving policy and practice guidelines on the management of individuals with this illness. In particular, the goal of this study was to determine whether patient characteristics especially symptoms of schizophrenia caused more caregiver burden/distress or if caregiver characteristics were more predictive of the burden/distress levels.

## METHODS

### Setting

The study was conducted at the Obafemi Awolowo University Teaching Hospitals Complex (O.A.U.T.H.C.), Osun State, southwestern Nigeria. Permission to carry out the study was granted by the ethics and research committee of the institution. Informed consent was obtained from participants and relatives after the aims and objectives of the study had been explained to them. The Hospital is a government funded public facility, and the psychiatric unit provides psychiatric services to Osun, Ekiti, Ondo and neighbouring states in southwestern Nigeria, with a catchment population of about 10 million people (Nigerian National Population Commission, 1998). English is the official language of the area, and all residents speak Yoruba which is the main language of the region.

### Participants

Participants were consecutively recruited from the outpatient psychiatric clinics of O.A.U.T.H.C., after having given informed consent. The patients had been diagnosed with schizophrenia using the DSM-IV guidelines, and this diagnosis was confirmed by a clinician who had been trained in the use of the Structured Clinical Interview for Axis I and II DSM-IV Disorders (SCID) (Spitzer et al., 1989). Patients included in the study had come in for follow-up appointments to the clinic, were in stable clinical condition, had been ill for at least one year, and were aged 65 years or less. Patients with mental retardation and serious physical disability were excluded from the study.

The primary caregiver of all patients included in the study had to be related either biologically or by marriage to the patient and had to fulfill at least one of the following criteria for inclusion in the study: 1) Living in the same household with the patient for at least six months before becoming involved in the study ; 2) Responsible for accompanying the patient to the hospital periodically to ensure that clinic appointments were kept; 3) Gave financial assistance to the patient to offset treatment cost like the purchase of drugs, laboratory investigations, hospital admission costs and transportation costs; 4) Not suffering from a clinicallydiagnosed mental illness/physical disability. A total of 101 caregiver/patient pairs who fulfilled the inclusion criteria were enrolled in the study between May 2008 to November 2008.

### Patient Symptom Assessment

Positive and Negative psychotic symptoms of patients were rated individually by the author using the 24 item version of the Brief Psychiatric Rating Scale (BPRS) (Overall & Gorham, 1962) and the 24 item version of the Scale for the Assessment of Negative Symptoms (SANS) (Andreasen1989), respectively. The positive symptoms included hallucinations, unusual thought content, conceptual disorganization and suspiciousness which were rated on a seven point scale of severity ranging from 1(“ not present “) to 7 (“ extremely severe”).

The negative symptoms included five symptom clusters of affective flattening , alogia, avolition/apathy, anhedonia/asociality and attention. These symptoms were rated using a five point scale (1= “not present”; 5= “severe “). Patients were also interviewed with a questionnaire that elicited socio-demographic variables. The BPRS and SANS have been used in previous studies in Nigeria ( Makanjuola & Adedapo, 1987; Ukpong et al., 2002; Ukpong, 2006). The patients and relatives were assessed separately.

### Family Caregiver Assessments

The caregivers completed the 30-item General Health Questionnaire (GHQ-30) (Golberg&Hiller 1979) which was used to measure emotional distress, and a 22-item questionnaire , the Zarit Burden interview (ZBI)(Zarit et al., 1980) to measure burden. The ZBI is a list of statements, reflecting how someone taking care of an ill person sometimes feel (ratings are on a 5-point Likert scale), and scores range from 0-88, with higher scores indicating increased burden. With the ZBI scale levels of burden are categorized as little or no burden (0-20), mild/moderate (21-40), moderate/severe (41-60), and severe burden (61-88).

The ZBI was developed to assess caregiver burden in relatives of patients with dementia, but it has also been used to assess burden in relatives of patients with schizophrenia in previous studies (Hanzawa et al.,2008)

The GHQ-30 and ZBI are self report instruments that have been standardized and used extensively in Nigeria, and the Yoruba version is available ( Gureje ,1991; Abiodun ,1994; Ukpong et al.,2003; Ukpong,2006;Yusuf et al., 2009). Literate relatives completed the screening instruments in English or

**Table 1.** Characteristics of caregivers and Patients N(101)

| Caregivers | Variables |
|---|---|
| Age in years, Mean ± SD (Range) | 51.3±15.5 (23-72) |
| Male gender , n (%) | 42 (41.6) |
| Spouse or parent of the patient, n (%) | 73 (72.3) |
| Education, secondary level or higher , n (%) | 62 (61.4) |
| Presently Employed n (%) | 51 (50.5) |
| Living with Patient | 81 (79.2) |
| Zarit Burden Interview score, Mean ± SD(Range) | 32.6±14.1 (13-59) |
| GHQ-30 score, Mean ±SD (Range) | 5.3±6.1 (0-20) |
| **Patients** | |
| Age in years, Means ± SD (Range) | 32.5±10.8 (19-58) |
| Male gender , n (%) | 80 (79.2) |
| Education, secondary level or higher , n (%) | 80 (79.2) |
| Presently Employed n (%) | 21 (20.8) |
| Duration of Illness in years, Mean ± SD (Range) | 9.8±7.3 (2-25) |
| Number of admissions | 1.6±1.29 (0-6) |
| BPRS Positive symptoms Score , Mean ± SD (Range) | 9.0±6.1 (0-20) |
| SANS Subscale Scores | |
| Affective Flattening or Blunting, , Mean ± SD (Range) | 1.0±1.2 (0-3) |
| Avolition-Apathy, , Mean ± SD (Range) | 1.7±1.5 (0-4) |
| Anhedonia-Asociality, , Mean ± SD (Range) | 1.8±1.4 (0-4) |
| Alogia, , Mean ± SD (Range) | 1.2±1.4 (0-3) |
| Attention, Mean ± SD (Range) | 1.03±1.2 (0-4) |

Yoruba. A trained research assistant read out the questions and marked the responses of those relatives that were unable to do so themselves. The threshold of discrimination between caseness and non-caseness on the GHQ-30 was 5.

### Analysis

Data were analyzed using SPSS 15 (SPSS Inc., Chicago, Illinois). Parametric statistics (t-tests, one-way ANOVA and Pearson's correlation) were used because the ZBI and GHQ-30 scores were fairly normally distributed. The ZBI and GHQ-30 scores were used as dependent variables in a stepwise multiple regression analysis. The independent variables were entered in the following steps: (1) caregiver's and patient's socio-demographic characteristics; (2) Patient's BPRS and SANS scores. A p value of less than 0.05 was considered statistically significant.

## RESULTS

Of the 120 caregivers who were recruited into the study , 8 caregivers did not consent to be in the study when first approached and 11 caregivers later withdrew consent before their assessments could be completed. Thus the 101 (84.2%) patient and caregiver pairs discussed in this article are those that gave consent to participate in the study. The characteristics of patients and caregivers are presented in Table 1. More than three-quarter of the patients were male and more than half of the caregivers were female. The caregivers were older than their patients relatives ( mean age 51.3 versus 35.2 years). In this study, 72% of caregivers were parents or spouses of patients and nearly 80% of caregivers lived with the patient. Descriptive statistics of caregivers ZBI and GHQ-30 scores and patients' SANS (subscale scores) and BPRS positive symptoms scores are listed in Table 1.

### Factors associated with caregiver burden-family caregiver characteristics

Caregiver GHQ-30 and ZBI scores were not significantly associated with sex or marital status. There was a tendency for caregivers with lower levels of education to have higher GHQ-30 scores and higher burden scores than those with higher education ( F=43.5, df=3/97, P=.001; F=4.7,df=3/97, P=.004). Significantly higher levels of caregiver burden were associated with living in the same household as the patient (t=5.52 , df=99, P=.000).

### Factors associated with caregiver burden- patient characteristics

#### Socio-demographic characteristics

There was no significant association between the patients' level of education and caregiver GHQ-30 scores. Caregivers of married patients had significantly higher levels of emotional distress than those caring for unmarried patients ( F=23.5,df=3/97,P=.000), and those caring for female patients experienced more emotional distress than those who cared for male patients (t=2.9,df=99,P=.005). Caregivers of patients with lower levels of education experienced more burden than caregivers of patients with higher educational attainment (F=9.3, df=2/98,P=.000). Caregivers of unemployed patients reported more burden than those of employed patients (t=3.90, df=99,P=.000),and a trend to experience higher levels of emotional distress even, though the relationship was not significant (t=1.71,df=99, P=.091) There was no association between burden and marital status of patients.

### Correlation with emotional distress/burden and psychopathology

In bivariate correlations, caregiver GHQ-30 scores were associated with positive symptoms of schizophrenia (p=.22, P=.02), and were also highly correlated with negative symptoms of attentional impairment in the patient (p=.45, P=.000). There was also a strong inverse relationship between GHQ-30 scores and affective flattening or blunting (p=-27., P=.006) Caregiver ZBI scores were strongly associated with anhedonia/asociality subscale (p=.37, P=.000). However, there was an inverse association between ZBI scores and affective flattening/blunting (p=-.28, P=.005). These results are shown in Table 2.

**Table 2.** Correlations between symptoms (n=101)

| | ZBI | GHQ-30 | BPRS | AFLN | ALOGIA | AVOLITION | ASOCIALITY | ATTENTION |
|---|---|---|---|---|---|---|---|---|
| ZBI | | | | | | | | |
| GHQ-30 | .60** | | | | | | | |
| BPRS | .14 | .22* | | | | | | |
| AFLN | -.28** | .27** | -.50** | | | | | |
| ALOGIA | -.133 | .11 | -.52** | .72** | | | | |
| AVOLITION | -.068 | .18 | -.44** | .64** | .88** | | | |
| ASOCIALITY | .37** | .03 | -.04 | .26** | .46** | .56** | | |
| ATTENTION | .012 | .45** | .03 | .15 | .52** | .58** | .21* | |

* p< .05 , **p<.01, AFLN: Affective Flattening or Blunting

**Table 3.** Regression Analyses Predicting Burden and Distress in caregivers

| Variables | Standardized β | t | P | R2 | F | P |
|---|---|---|---|---|---|---|
| Burden (ZBI) (Dependent) | | | | 0.28 | 19.4 | .001 |
| Asociality-anhedonia | 0.472 | 5.34 | .001 | | | |
| Affective Flattening or Blunting | -0.397 | -4.48 | .001 | | | |
| Demographic variables | | | | 0.25 | 10.8 | .001 |
| Patient's unemployment | -0.351 | -3.08 | .001 | | | |
| Duration of illness | 0.266 | 2.99 | .003 | | | |
| Caregivers' education | -.261 | -2.95 | .004 | | | |
| Emotional Distress (GHQ-30) (Dependent) | | | | 0.35 | 17.4 | .001 |
| Inattention | 0.350 | 3.23 | .002 | | | |
| Avolition | 0.302 | 2.17 | .033 | | | |
| Affective Flattening or Blunting | -0.514 | -4.49 | .001 | | | |
| Demographic variables | | | | | | |
| Female sex | -0.318 | -3.42 | .001 | 0.24 | 10.1 | .001 |
| Patient's education | -0.394 | -4.04 | .000 | | | |
| Duration of illness | -0.311 | -3.24 | .002 | | | |

### Multiple regression analyses (Table 3)

In the final regression models the following patterns emerged: (1) education of patient, patient's sex and duration of illness were significant predictors of total GHQ-30 scores; (2) educational status of the caregiver , employment status of the patient and duration of the illness were significant predictors of the ZBI scores; (3) when looking at the effect of patient psychopathology on GHQ-30 scores, impairment in attention, avolition and affective flattening/blunting were significant predictors of emotional distress. However, anhedonia/asociality and affective flattening or blunting were strong predictors of burden (ZBI scores). Using multivariate analyses, high levels of emotional distress were associated with the patient having a lower education level and being of the female gender. Higher burden was perceived by caregivers who took care of patients who were unemployed and who had a longer duration of the illness. Less educated caregivers also experienced higher levels of burden than those who were more educated.

## DISCUSSION

The present study examined the relationship between symptoms of schizophrenia and caregiver burden/distress using a cross-sectional descriptive design. The caregivers were predominantly women (58.4%), which was similar to previous studies(Sefasi et al.2007.;Dyck et al.,1999; Winefield and Harvey ,1993). More than one third of the caregivers in the sample (33.7%) were experiencing moderate/severe levels of burden (i.e. ZBI scores of 41-60) (Zarit et al.,1980). The mean GHQ-30 score of 5.3±6.1 for the total sample was higher than the threshold of 5 for discrimination between cases and non cases (Golberg and Hiller,1979).

Other similar studies also reported high levels of burden and distress (Yusuf et al.,2009). Caregivers' emotional distress in this study was associated with patient's positive and negative symptoms, whereas caregiver burden was related to only negative symptoms. These findings support those of Provencher and Mueser (1997), that subjective burden of care was related to both positive and negative symptoms whereas objective burden of care was only related to negative symptom behaviors. In this study, the most potent influence on caregiver burden was negative symptoms in the patient, especially anhedonia-asociality. The next strongest relationship was that between emotional distress of the caregiver and attentional impairment in the patient, followed by the negative symptom of avolition-apathy in the patient. These findings are in line

with previous research using direct measures of symptoms. In a longitudinal study by Raj et al (1991) in India, negative symptoms correlated strongly with family burden, and in the UK study by Oldridge and Hughes(1992), negative symptoms had a very significant correlation with caregivers' emotional distress.

There was however an inverse relationship between affective flattening or blunting and burden/distress. It is plausible that caregivers could cope with these group of negative symptoms, and hence to not find them to be burdensome.

This study found no association between caregiver gender and burden/distress levels, unlike some previous studies where gender differences were observed (Yusuf and Nuhu,2009).

The finding in this study that caregivers with lower education experienced higher levels of burden and higher levels of emotional distress than their counterparts with higher levels of education is also supported by previous research( Zahid and Ohaeri, 2010).

Caregivers of patients with lower levels of education also exhibited higher burden levels than caregivers of patients with higher levels of education, and this was significant.

A higher education guarantees better job opportunities and may convey some socioeconomic advantage, apart from influencing one's health seeking behavior. A caregiver with a low level of education would have limited access to mental health facilities because of limited resources, and may be at risk of developing emotional distress because of this additional disadvantage.

These findings support those of previous reports (Zahid and Ohaeri, 2010). This study also found that caregivers of female patients reported significantly higher levels of emotional distress than caregivers of male patients. This finding though uncommon is supported by some other reports (Winefield and Harvey,1993;Zahid and Ohaeri,2010), in some other studies the converse has been observed (Roick et al 2007; Yusuf and Nuhu, 2009).

Patient unemployment in this study was associated with high levels of emotional distress, thus supporting previous findings that family members experienced less burden when the ill person was employed ( Pickett et al.,1995). Finally, the results of the regression analysis with burden (ZBI) and emotional distress (GHQ-30) as dependent variables, support the results of previous studies highlighting the significance of negative symptoms of schizophrenia as strong predictors of burden and distress in caregivers ( Raj et al.,1991; Gopinath and Chaturvedi,1992)

## CONCLUSIONS

The burden of responsibility in caring for relatives with schizophrenia is worsened by negative symptoms of the disorder. More work is needed on larger samples to determine how caregivers and relatives cope with symptoms of the illness. Longitudinal studies are needed to investigate the health and mental health sequelae of caregiving among family relatives of persons with schizophrenia.

### Limitations of the study

The study was cross-sectional and limited to one setting. The sample may not be representative of the total population of people in treatment or the total population of people with schizophrenia in Nigeria.

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