Original Article

Effects of Psychopathology, Functioning and Anti-psychotic Medication Adherence on Caregivers' Burden in Schizophrenia

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ABSTRACT

Background: The aim of the study was to determine the effects of the level of psychopathology and anti-psychotic medication adherence on caregivers' burden in schizophrenia. **Materials and Methods:** Three hundred and sixty-seven schizophrenia patient/caregiver dyads were interviewed. Caregiver's burden was assessed using the Yoruba version of the Family Burden Interview Schedule (FBIS) and 12-Item General Health Questionnaire (GHQ-12). Patients were assessed using the Global Assessment of Functioning (GAF) scale, Positive and Negative Symptoms Scale (PANSS), and medication compliance questionnaire. **Results:** Mean age of the patients was 29.7 SD (8.6) years. About 82% of the 368 caregivers were parents of the patients with mean age of 58.1 years (SD 19.6). Total mean objective FBIS score was 22.69 (6.21), with 324 caregivers (85.3%) reporting total objective burden and 310 (84.2%) reporting subjective burden. FBIS scores were positively associated with PANSS scores but negatively with GAF $P<0.001$, respectively. Mean FBIS reduced with medication compliance categories A and B, $P<0.01$, respectively, but increased in category F, $P<0.001$. In all, 51.1% scored ≥ 3 on GHQ. **Conclusion:** Caregivers of schizophrenia patients experience enormous burden and are at risk for mental disorders. The severity of this burden is related to the level of psychopathology and medication adeherence, thereby adding to the available evidence pointing to the need for clinicians to optimize patients' management to prevent psychological distress in carers of such patients.

Key words: *Anti-psychotic medication, caregiver's burden, psychopathology, schizophrenia, Yoruba version of family burden interview schedule*

INTRODUCTION

Many previous studies have shown an association between family burden and socio-demographic as well as personality variables of caregivers[1,2] or expressed emotion.[3]

Some others have indicated that patients' factors such as symptom severity and clinical characteristics such as suicidal ideation, behavioral disturbances, and negative symptoms predict high level of caregivers' burden in psychotic persons.[4-10] There is increasing recognition of the importance of impact of psychotic disorders on functioning.[11] This is because, in considering recovery from psychosis, as supported by the personal stories of people with psychosis, it is acknowledged that improved functioning does not equate with, or automatically

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follow from, resolution from psychotic symptoms.[12,13] Thus, people with psychoses have emphasized improved functioning as distinct from symptom resolution to their experience of recovery.[14-16]

There is a need for more research efforts in order to identify the impact of the clinical variables and functioning in psychosis on family burden, so also is the role of medication adherence. It is also important to determine whether they have equivalent or rather a differential effect.

We have reported the socio-demographic and other correlates of caregivers' burden in an earlier publication.[17] The main objective of this study was to determine the effects of the level of psychopathology and anti-psychotic medication adherence on caregivers' burden in schizophrenia. Our findings using the validated Yoruba version of Family Burden Interview Schedule (Y-FBIS)[18] are reported therein.

MATERIALS AND METHODS

The methodology has been described elsewhere.[17] Briefly stated, study was carried out at the Psychiatric Unit of the Ring Road Specialist Hospital, Ibadan, Nigeria. The sample population was constituted by dyads of patients with a principal diagnosis of schizophrenia and their respective caregivers recruited between January and December, 2007. Diagnosis of schizophrenia was made in the patients using the Structured Clinical Interview for Diagnostic and Statistical Manual Fourth Edition (DSM IV) axis I disorder (SCID)[19] after an initial psychosis screening.[20] Patients with any additional DSM IV axis I, any axis II, or axis III diagnoses were excluded from the study.

For the purpose of this study, we defined a "principal caregiver" as "a non-professional non-paid person in the community who was most involved with the everyday care of the case and would be very likely to respond to any request for special assistance at any time, if such a request was made by the case."[21] The recruited caregivers have lived exclusively with the index patient for at least 1 year prior to recruitment and were not involved in the care of any other family member with any mental or chronic physical illness. They were also Yoruba speaking Nigerians of either gender aged 18 and above and were able to understand the exercise.

Setting of the interview
We conducted a face-to-face interview with each patient and the principal caregiver. Caregivers were confidentially interviewed in order to facilitate their free expression. The interview took place at the special Clinic of the Ring Road State Hospital. Each interview took between 40 min and 50 min to complete.

Both the patients and their respective caregivers provided written informed consent and Ethical approval to conduct the study was obtained from Ethical Review Committee of the Department of Planning, Research and Statistics, Ministry of Health, Oyo State, Nigeria.

MEASURES

Caregivers
The family burden interview schedule
This scale in its original form measures objective and subjective aspects of burden and it contains six general categories of burden, each having two to six individual items for further investigation. Subcategories include: Financial burden, effects on family routine, effects on family leisure, effects on family interaction, effects on physical health of family members, and effects on mental health of other family members. Each item is rated on a three-point scale, where 0 is no burden and 2 is severe burden.[22] The Y-FBIS has been validated among Yoruba-speaking Nigerian caregivers. Internal consistency of the Y-FBIS was demonstrated by a significant Cronbach's α of between 0.62 and 0.82 for each item. Test–retest reliability of individual scales ranged from 0.780 to 0.874 and was 0.830 for total objective scale score.[18]

Patients
Global Assessment of Functioning (GAF) scale is a 100-point single-item rating scale used by a clinician to determine overall functioning of a patient during a particular time. The GAF is viewed as a composite of three major domains: Social functioning, occupational functioning, and psychological functioning.[23] The GAF is derived from the Global Assessment Scale (GAS) which has established psychometric properties. Joint reliability on the GAS and the GAF scale across several studies ranged from 0.61 to 0.91 indicating fair to excellent agreement.[24] The functional level of the patient over the past 1 month was assessed in this study with GAF.

Positive and Negative Syndrome Scale (PANSS) is a 30-item, seven-point rating instrument that has adapted 18 items from the Brief Psychiatric Rating Scale[25] and 12 items from the psychopathology rating schedule.[26] Each item on the PANSS is accompanied by a complete definition as well as detailed anchoring criteria for all seven rating points, which represent increasing levels of psychopathology from 1 indicating absence to 7 which denotes extreme symptoms. The PANSS addresses both the presence and severity of symptoms, and the highest applicable rating point is always assigned, even if the patient meets criteria for lower ratings as

well. Of the 30 psychiatric parameters assessed on the PANSS, 7 were chosen *a priori* to constitute a positive scale, 7 make up a negative scale, and the remaining 16 general psychopathology.

Medication adherence questionnaire is a four-item self-report scale[27] that identifies ways in which patients may fail to take their prescribed medications e.g., by forgetting, not taking it because they feel better, or not taking it because it makes them feel worse. It is available in two versions, the first being the original version with a binary response option (no/yes) and with scores ranging from 0 to 4. The second version is a five-point response version (never/rarely/sometimes/often/always having scores that range from 0 to 16), higher scores indicating worse adherence. The scale was successful in predicting positive therapeutic outcomes and has been used in some studies in Nigeria.[28,29] The five-point response version was used in this study with modification of the second question because the word "careless" may be misunderstood as not keeping the medication safely and may also convey a derogatory meaning. Hence, it was replaced with the word "carefree." Those who responded "never" or "rarely" to all the items on the scale were classified as medication adherent, whereas those who responded "sometimes/often" or "always" to any of the questionnaire items were classified as non-adherent.

Intervention

The intervention consisted of weekly guidelines – counseling given to the patients and caregiver by trained public health nurses, thereby helping them with treatment adherence. In the Intervention condition, haloperidol 0.07 mg/kg or olanzapine 0.07 mg/kg was administered to all patients. Patients were also followed up throughout the period of study by telephone call to achieve treatment adherence.

Statistical analysis

The data analysis was according to the two objectives. An estimate of the prevalence and correlates of family burden was obtained and analysis of continuous variables carried out with student test and ANOVA. For categorical data, Chi-square statistics was used for analysis. Significant level was set at 0.05, two-tailed. All analyses were performed with the SPSS, version 15.0.[30]

RESULTS

Four hundred and eight patients with the DSM IV diagnosis of schizophrenia according to the SCID were assessed for their eligibility to enter the study. Forty of them were excluded for various reasons including absence of caregiver, multiple diagnoses, medical co-morbidity, and refusal to give consent. As a result, 368 patient–caregiver dyads were recruited.

Majority of the caregivers interviewed (81.5%) were parents. Gender distribution was skewed with 286 (77.8%) being females. A larger proportion of the caregivers, 302 (82.9%) were single, separated, widowed, or divorced. Their age ranged from 18 to 82 with a mean of 58.1 years (SD=19.6), median was 51 years, 51.1% of the caregivers scored 3 and above on the GHQ [Table 1].

Mean burden score in the domain of financial burden was 5.85 (2.24), disruption of routine family activities was 4.89 (1.88), disruption of family leisure was 4.74 (2.03), disruption of family interaction was 4.42 (1.83), effect on physical health of others

Table 1: Socio-demographic characteristics of patients and caregivers

Socio-demographic characteristics	Patients frequency	%	Caregivers frequency	%
Age group (years)				
<25	145	39.4	8	2.2
25-34	145	39.4	36	9.8
35-44	61	16.6	88	23.9
>44	17	4.6	122	33.1
Years of education				
Nil	76	20.6	180	48.9
1-6	181	49.2	128	34.8
7-12	90	24.5	32	8.7
>12	21	5.7	28	7.6
Gender				
Male	214	58.1	80	21.7
Female	154	41.9	288	78.3
Marital status				
Married	61	16.6	62	16.8
Single	163	44.3	64	17.4
Separated	118	32.1	172	46.7
Divorced	11	3.0	40	10.9
Widowed	5	1.4	30	8.2
Occupation**				
High level professional	2	1.1	-	-
Skilled worker	24	6.5	9	2.4
Semi-skilled worker	44	11.1	12	3.3
Unskilled worker	45	11.1	210	57.1
Unemployed	253	68.8	137	37.2
Relationship of caregivers to patient				
Either parent	-	-	219	59.5
Spouse	-	-	43	11.7
Sibling	-	-	49	13.3
Distant family member	-	-	30	8.2
Non-relations	-	-	27	7.3
Mean duration of illness	2.94 SD (1.95)	-	-	-
Mean hours spent with patient	-	-	14.45 SD (5.70)	-
GHQ of caregivers				
≤2	-	-	180	40.9
≥3	-	-	188	51.1

GHQ – General health questionnaire; SD – Standard deviation; **The occupation variable used was a modified version of a scale developed by Pineo, Porter and McRoberts[36]

was 1.32 (0.72), and effect on mental health of others was 0.99 (0.39). Total mean objective score was 22.69 (6.21) and mean subjective score was 1.12 (0.68) [Table 2].

Mean PANSS score significantly reduced with increased GAF, $F=14.3$, $P<0.001$. Mean FBIS score also significantly reduced with increased GAF, $F=10.6$, $P<0.001$ [Table 3].

There was a significant reduction in mean FBIS among patients who were compliant on their medications in categories A and B, $P<0.01$, respectively. There was also a significant increase in mean FBIS among patients who were medication compliant in category F, $P<0.001$.

DISCUSSION

This study aimed at determining the effects of severity of psychopathology and anti-psychotic medication adherence on caregivers' burden in schizophrenia. In this study, the results showed that the FBIS scores were positively associated with PANSS scores but negatively with GAF. Mean FBIS score also reduced with medication compliance in areas of financial burden and disruption of routine family activities but increased in the area of "Effect on mental health of others."

To the best of the authors' knowledge, this is the first study in Nigeria that determined the association between functioning in psychosis and family burden as well as the effect of anti-psychotic medication on family burden.

The socio-demographic profiles of the caregivers in this study are generally in contrast to a study carried out in China that utilized same caregivers burden instrument.[31] This is because results from this study indicate that caregivers were generally older, had fewer years of education, fewer proportions were married but a larger proportion were either unskilled workers or unemployed. The mean FBIS scores reported were also generally lower than the baseline figures in that study. Generally, these low mean FBIS figures may be potentially ascribed to the effect of social network and effective support system in Nigeria.[5]

This study also found that FBIS scores had a positive association with PANSS score but a negative one with GAF score. This emphasizes the impact of the symptom profile and functioning in schizophrenia on family burden. This finding supports a report by Ukpong[32] in Nigeria who noted that family burden was significantly associated with positive and negative symptoms of schizophrenia. Justifiably, less psychotic individuals would create lesser burden of caring than disturbed patients. This result was further corroborated

by the finding that there was a significant reduction in mean FBIS among patients who were compliant on their medications in the area of "financial burden" and "disruption of routine family activities" [Table 4]. It is possible that some of these schizophrenia patients who

Table 2: Pattern of objective score at category and item levels

Categories/items	Mean category/item score	SD
Financial burden	5.85	2.24
Disruption of routine family activities	4.89	1.88
Disruption of family leisure	4.74	2.03
Disruption of family interaction	4.42	1.83
Effect on physical health of others	2.25	1.05
Effect on mental health of others	2.05	0.87
Total objective score	22.69	6.21
Subjective score	1.12	0.68
Total objective and subjective	23.81	6.30

SD – Standard deviation $n = 368$

Table 3: Association between GAF score, PANSS score, and FBIS score

GAF %	Mean PANSS	SD	Mean FBIS	SD
20-29	105.00	-	25.00	-
30-40	101.71	30.64	23.69	-
41-50	93.91	33.47	24.15	6.07
51-60	80.58	30.81	25.23	5.03
61-70	72.40	26.18	23.70	4.10
71-80	82.61	31.12	19.84	4.54
81-90	56.36	31.30	20.21	4.09
90-100	67.70	38.00	13.30	7.68
F	14.3		10.6	
P	<0 001		<0.001	

SD – Standard deviation; GAF – Global assessment of functioning; PANSS – Positive and negative syndrome scale; FBIS – Family burden interview schedule

Table 4: Relationship between family burden and compliance with medication

Y-FBIS category	Medication compliant	Mean	SD	t	P
Financial burden	No	6.39	1.92	2.6	<0.01
	Yes	5.68	2.30		
Disruption of routine family activities	No	5.39	1.54	2.8	<0.01
	Yes	4.74	1.96		
Disruption of family leisure	No	4.64	1.76	−0.5	0.6
	Yes	4.77	2.11		
Disruption of family interaction	No	4.28	1.41	−0.8	0.4
	Yes	4.47	1.94		
Effect on physical health of others	No	2.06	0.94	−2.0	0.05
	Yes	2.31	1.07		
Effect on mental health of others	No	1.20	0.92	−3.8	<0.001
	Yes	1.57	0.72		
Total objective	No	23.59	5.01	1.6	0.1
	Yes	22.41	6.52		

SD – Standard deviation; Y-FBIS – Yoruba version of the family burden interview schedule

were medication compliant were going into remission and would require less frequent hospital visits and medication, hence reduced mean FBIS score, thereby creating lesser burden in these areas. This supports the report of Ohaeri[1] in Nigeria, that disturbed behavior is a greater determinant of severity of burden than psychiatric diagnosis; hence, adequacy of treatment is a first step in reducing caregiver burden.

This study also found that mean FBIS score was higher among those who were medication compliant in some categories of caregiver's burden (effect of illness on physical health of others and effect of illness on the mental health of others) [Table 4]. There are a couple of possible explanations for this. One is that compliance with medication does not equate resolution from psychotic symptoms; more so, resolution from psychotic symptoms does not equate adequate functioning.[12-16] Thus, the pathways to improved functioning and recovery for individuals or groups of individuals receiving particular services are likely to be more varied and complex. Another potential explanation is that the act of medication administration and supervision is an area that is quite burdensome in some dimensions of caregivers' burden.

The above findings have both policy and clinical implications. In most developing nations, including Nigeria, general and mental health indices are poor and generally patients pay out of pocket.[33] In the light of the above findings, it is imperative that clincians optimize patients' care in terms of anti-psychotic medications. This in itself, however, is not sufficient as medication non-adherence and clinic default remain major challenges in treatment of schizophrenia.[34] Even with good compliance, more than 30% of patients with schizophrenia will not respond adequately to standard medication.[35] This therefore calls for other interventions such as social and occupational rehabilitation for patients, as well as psychoeducational programmes and psychosocial support for families and caregivers of patients with schizophrenia. Health policies should also be geared toward increased availability and funding of these programs.

This study was limited by a number of factors. The Y-FBIS like the English version does not have cut-off points that may serve as focus of clinical intervention. It is rated over only three points: No burden, moderate burden, and severe burden. Thus, it requires more anchor points for the response to give a more meaningful interpretation.

A structured personality and Intelligence Quotient (IQ) assessments were not carried out to determine whether the patients had intellectual impairment or personality disorder, as these could have created additional burden to the care of the patients.

Risk factor analysis was not carried out and this has greatly limited the interpretation of various bivariate relationships.

ACKNOWLEDGMENTS

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