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Correlates of Quality of Life in Caregivers of Patients with Schizophrenia and Bipolar Affective Disorder: A Study From Southwestern Nigeria

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SUMMARY

Objective: Quality of life and its correlates were studied in two groups of family caregivers of patients with major mental disorders-Schizophrenia (SZ) and Bipolar Affective Disorder (BPAD).

Method: Family caregivers of SZ and BPAD patients were consecutively recruited to the study (n=100 for each group). Caregivers were screened for quality of life (QOL) measures, caregiver burden, symptoms of anxiety and depression, using the World Health Organization Quality of Life Scale (WHOQOL-BREF), the Pai and Kapur Family Burden Interview Schedule (FBIS) and the Hospital Anxiety and Depression Inventory (HADS) respectively.

Results: When compared to the caregivers of the BPAD patients, the caregivers of the SZ patients had lower QOL scores in two out of the 4 WHOQOL-BREF domains (physical and psychological domains)(p=0.001), and higher overall total caregiver burden (p=0.001).

On the other hand, caregivers of the BPAD patients had higher levels of depressive symptoms (p=0.001). Increased depressive symptoms were associated with lower QOL for both groups, comprising all WHOQOL-BREF domains for BPAD and 3 domains for SZ caregivers. Higher caregiver burden was associated with lower QOL for both groups.

Conclusion: There is a need for intervention and caregiver support for the relatives of patients with bipolar disorder and schizophrenia.

Keywords: Quality of Life, caregiver burden, depression, correlates

INTRODUCTION

As a consequence of de-institutionalization, the burden of caregiving in families of the mentally ill has increased, and this may not be unconnected with the declining number of long stay psychiatric institutions over the years in most countries.

The measurement of family burden of psychiatric illness has largely been driven by the methodological advances made by Hoenig and Hamilton (1966), with their seminal concept of objective and subjective burden of caregiving. Since then related studies have shown that high distress and burden levels may be associated with caring for a mentally ill family member (Tristiana et al. 2019, Ibigbami et al. 2018, Ukpong 2012, Barrowclough 2005, Chakrabarti and Kulhara 1999).

Comparative studies measuring levels of burden across a range of psychiatric illnesses have also confirmed the relevance of their negative impactamong family caregivers of schizophrenia patients (Chakrabarti and Kulhara 1999, Chakrabarti and Gill 2002). Studies on the families of BPAD patients are more limited, but indicate that family members of persons with bipolar disorder also experience considerable subjective distress just like their counterparts caregiving for schizophrenia (Perlick et al. 1999, Ibigbami et al. 2018).

In addition to the significant burden of caregiving on families, there may be considerable adverse health effectsincluding high levels of depression, poor physical health, low levels of subjective well-being and poor quality of life (Tristiana et al. 2019, Rossler 2006). It is noteworthy that this task is not chosen voluntarily by the families.

While relatives continue to be regarded as exploitable sources of information, the burdensome effects of caregiving on the quality of life of these families are often ignored.

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Quality of life studies on caregivers of mentally ill patients are uncommon in Nigeria, despite the enormous social and economic burden experienced by primary family caregivers of persons with severe mental illness in the country.

To address this gaps in knowledge, the present study was designed with the following objectives:

1. To investigate the quality of life of the family caregivers of patients with BPAD or schizophrenia.
2. To examine the impact of caregiver burden, caregiver and patient socio-demographic and clinical variables comprising duration of caregiving, caregiver anxiety or depressive symptoms, duration of illness and number of previous hospital admissions on caregiver QOL.

METHOD

Participants

Participants were consecutively recruited from the outpatient clinics of the two psychiatric units of Obafemi Awolowo University Teaching hospital, Ile-Ife, Nigeria, after obtaining their informed consent. The patients included in the study arrived at the clinic for follow up appointments in stable clinical condition. They had been ill for at least one year prior to joining the study and had been diagnosed with schizophrenia or BPAD using the ICD-10 (WHO1992) diagnostic guidelines. The diagnoses were confirmed by a clinician using the Mini-International Neuropsychiatric Interview (MINI), a short structured diagnostic interview designed for DSM-IV and ICD-10 psychiatric disorders (Sheehan et al. 1998). Patients with mental retardation, substance abuse and serious physical disability were excluded from the study.

Selection of family caregiver was based onmeeting at least threeout of five criteria established by Pollak and Perlick (1991): (I) being a spouse or parent; (ii) having more frequent contact than any other caregiver; (iii) helping to support the patient financially; (iv) being the contact by treatment staff for emergencies; (v) being involved in the patient's treatment. Families with more than one mentally ill member or another member with chronic physical illness were excluded from the study. The study was cross-sectional and only healthy relatives aged 18 years and older living with the patient for a minimum period of 1 year were eligible for inclusion in the study. A total of 200 caregiver/patient pairs who satisfied the selection criteria were admitted to the study between August 2010 and March 2011. The study was approved by the Hospital Ethics and Research committee.

Assessment Instruments

A pro-forma questionnaire was used to acquire data on the socio-demographic variables of patients and caregivers including duration of patient illness and of caregiving.

Caregiver burden was rated using the Pai and Kapur Family Burden Interview Schedule (FBIS) (Pai and Kapur 1981) which has 24 items grouped into six categories of burden comprising the effects on family finances, effects on family routine, effects on family interactions, effects on family leisure, effects on physical health of other family members and effects on mental health of other family members.

Each item of the FBIS can be marked as absent (score = 0), moderate (score =1) or severe (score = 2). The FBIS has been used in previous Nigerian studies (Martyns-Yellowe 1992, Ukpong 2009). In this study the section "Effect on mental health" was replaced with the 14-item Hospital Anxiety and Depression Inventory (HADS) in order to give a more comprehensive picture of emotional distress in the participants (Zigmund and Snaith 1983, Ukpong 2009).

Perceived QOL of caregivers was assessed with the brief version of the World Health Organization Quality of Life Scale (WHOQOL-BREF) (WHOQOL Group 1998). The WHOQOL-BREF is a 26 item questionnaire that measures 4 QOL domains: Physical, Psychological, Social relationships and Environmental. It also contains two questions that examine self-perception of overall QOL and health. Each of the 26 items is rated on a 5 point Likert type scale of 1 to 5, with higher scores reflecting better quality of life. QOL scores were calculated according to the WHO standardized algorithm on a scale of 4-20 to be comparable with WHOQOL-100.

Statistical Analysis

The IBM SPSS software version 23 was used to store and analyze data. Results were computed as frequencies (%), means, and standard deviations (SD) for normally distributed variables. Differences between groups were analyzed using the independent samples t test for continuous variables. Categorical variables were analyzed using the Chi-square statistic. Pearson's (r) and Spearman's ρ (for ordinal variables where appropriate) were computed for selected variables.

Multiple regression analysis was performed to single out which characteristics of the caregivers and patients were most predictive of caregiver QOL as measured by the scores on self-perception of overall QOL of the WHOQOL-BREF. Independent variables comprised the age, duration of caregiving, caregiver burden, and HADS depression scores of the caregivers; and the characteristics and clinical features of the patients including gender, illness duration, number of hospital admissions. These parameters were included because they were found to show group differences.

The level of statistical significance was set at 0.05. All tests were two tailed.

RESULTS

Participant Characteristics

The two groups of participants consisted of the primary caregivers of 100 schizophrenia and 100 BPAD patients and their respective patient relatives. The characteristics of the participants are summarized in Table 1. The mean age of the schizophrenia patients (31.33±10.60 years) was comparable to that of the BPAD patients (33.14±14.02 years).

The duration of illness was significantly longer for the BPAD than for the schizophrenia group of patients (t=7.1; p<0.001).

Employment status of the two patient groups were similar and both groups were more likely to remain unmarried.

There were significantly more female patients in the BPAD group than in the schizophrenia group.

The schizophrenia caregivers were older than their BPAD counterparts (t=7.1; p=0.001).

For the entire cohort(N=200), the primary caregivers were mostly parents (70%), with siblings (16.5%), spouses (2.5%) and adult children (10%) making up the rest.

Burden and Psychological Distress

Comparisons of the QOL domain dimensions, caregiver burden categories and psychological distress scores are summarized in Table 2.

In the caregiver groups, heaviest burdens were felt in the financial domain, effects on family routine, effects on family leisure and effects on family interaction. Burden levels were significantly lower in the BPAD group compared to the schizophrenia group of caregivers. The total burden score for the BPAD group was significantly lower than the score for the schizophrenia group of caregivers (t=5.2; p=0.001).

The HADS anxiety symptom scores of the two groups of caregivers did not differ significantly. However, the caregivers of the BPAD group had significantly higher mean HADS depression symptom scores than the caregivers of the schizophrenia group (t=3.2 ; p=0.001).

Caregiver Quality of Life

The QOL scores of the caregivers of schizophrenia patients were significantly lower as compared to the caregivers

Table 1. Socio-Demographic and Clinical Variables of the Participants

Parameters	BPAD n=100	Schizophrenia n=100	t/χ^2
Patient variables			
Age in years	33.14 (14.02)	31.33 (10.60)	t=1.02 p=0.31
Illness duration	11.39 (10.35)	6.57 (4.54)	t=4.24 p=0.001
No. of hospital admissions	0.91 (1.15)	0.47 (.79)	t=0.39 p=0.002
Males	19	62	χ^2=37.4
Females	81	38	p=0.001
Married	11	8	χ^2=0.49
Unmarried	89	92	p=0.631
Employed	40	44	χ^2=0.24
Unemployed	60	56	p=0.667
Caregiver variables			
Age in years	43.03 (13.06)	56.13 (12.99)	t=7.12 p=0.001
Duration of caregiving	4.38 (3.07)	5.99 (4.53)	t=2.94 p=0.004
Males	48	37	χ^2=2.30
Females	52	63	p=0.085
Single	40	37	χ^2=0.145
Married	60	63	p=0.771
Employed	90	87	χ^2=0.47
Unemployed	10	13	p=0.515
Relationship to patient			
Spouse	0	5	χ^2=47.10
Parent	53	88	p=0.001
Sibling	27	6	
Child	20	1	

Table 2. Quality of Life, Caregiver-burden, Anxiety and Depression

Parameters	BPAD	Schizophrenia	Statistic (t test)
Overall Perception of QOL	3.73 (1.01)	3.34 (0.76)	3.04 p=0.003
Overall Perception of Health	3.94 (0.87)	3.29 (1.05)	4.72 p=0.001
QOL Domains			
Physical	13.69 (1.43)	12.78 (1.80)	3.95 p=0.001
Psychological	13.52 (1.68)	12.84 (1.98)	2.59 p=0.01
Social	13.81 (3.36)	13.71 (2.79)	0.23 p=0.815
Environmental	13.10 (2.51)	12.58 (2.27)	1.54 p=0.124
Burden Categories			
Financial	4.12 (2.47)	6.73 (3.33)	6.30 p=0.001
Effect on Family Routine	2.66 (2.25)	3.94 (2.87)	3.52 p=0.001
Effect on Family Leisure	1.06 (1.33)	2.05 (2.22)	3.81 p=0.001
Effect on Family Interaction	1.73 (2.30)	2.48 (2.54)	2.19 p=0.029
Effect on Physical Health of Other Family Members	0.57 (0.70)	0.60 (1.02)	0.29 p=0.773
Burden Total Score	10.14 (6.07)	15.85 (9.18)	5.15 p=0.001
HADS Anxiety	4.50 (3.60)	4.42 (3.14)	-0.15 p=0.875
HADS Depression	6.92 (3.59)	5.19 (3.94)	-3.20 p=0.001

of the BPAD patients on the Physical domain (t=3.95 p=0.001) and the Psychological domain (t=2.59; p=0.010) of the WHOQOL-BREF. For the Social relationships and Environment domains, the two groups of caregivers were comparable in their QOL scores (p>0.05; NS).

Correlates of Quality of Life– the BPAD group

Correlates that demonstrated a significant association with caregiver QOL are summarized in Table 3.

Older caregivers had deficits in psychological health and social relationships domain, as shown by strong negative correlations.

Poor physical health in caregivers was associated with caring for older patients.

Longer duration of illness was associated with deficits in the domains of psychological health and environment.

Longer caregiving experience inversely correlated with caregiver physical and psychological health, and the social relationships domain.

High level of caregiver burden was associated with deficits in all the QOL domains of caregivers.

Caring for employed patients was protective to caregiver QOL in the domains of social relationship and environment.

Caregivers who were employed suffered deficits in the domains of psychological health, social relationships and environment.

Unmarried patient status was associated with QOL deficits in domains of physical health, social relationships and environment of caregivers. Being a married caregiver correlated negatively with QOL domains of physical and psychological health.

High levels of depressive symptoms in the caregivers of BPAD patients correlated negatively with all the QOL domains, whereas high levels of anxiety symptoms in caregivers correlated negatively only with psychological and social relationships domains.

Correlates of Quality of Life – the Schizophrenia Group

Correlates that demonstrated a significant association with caregiver quality of life are summarized in Table 3.

The age of the caregivers of schizophrenia patients was inversely correlated with all the four QOL domains. There was a greater likelihood for caregivers of older patients to experience poor physical health.

Table 3. Correlates of quality of life in caregivers of BPAD and Schizophrenia patients

QOL-Bref Domains	Patients' age	Caregivers' age	Duration illness	Duration caregiving	Patients' Marital status	Caregiver Marital status	Patients' Employment	Caregiver Employment	Caregiver Burden	Caregiver Anxiety	Caregiver Depression
BPAD Group											
Physical	-.21(p=0.03)	-	-	-.41(p<0.001)	-.39(p<0.001)	-.25(p=0.01)	-	-	-.52(p<0.001)	-	-.36(p<0.001)
Psychological	-	-.21(p=0.03)	-.21(p=0.03)	-.27(p<0.001)	-	-.24(p=0.02)	-	-.20 (p=0.048)	-.42(p<0.001)	-.38(p=0.001)	-.23(p=0.02)
Social	-	-.27(p=0.006)	-	-.22(p=0.03)	-.25(p=0.01)	-	.24(p=0.02)	-.43(p<0.001)	-.73(p<0.001)	-.25(p=0.01)	-.28(p=0.004)
Environment	-	-	-.31(p=0.002)	-	-.56(p<0.001)	-	.34(p=0.001)	-.44(p<0.001)	-.72(p<0.001)	-	-.42(p<0.001)
Schizophrenia Group											
Physical	-.32(p=0.001)	-.38(p<0.001)	-.21(p=0.03)	-.22(p=0.02)	-.34(p=0.001)	-	.50(p<0.001)	-	-	-	-
Psychological	-	-.51(p<0.001)	-.24(p=0.01)	-.26(p=0.008)	-	-.37(p<0.001)	-	-	-.49(p<0.001)	-.22(p=0.02)	-.42(p<0.001)
Social	-	-.36(p<0.001)	-	-	-	-.35(p<0.001)	-	-	-.49(p<0.001)	-.21(p=0.03)	-.37(p<0.001)
Environment	-	-.27(p=0.007)	-.36(p<0.001)	-.34(p=0.001)	-	-.27(p=0.008)	-	-	-.43(p<0.001)	-.50(p<0.001)	-.47(p<0.001)

Table 4. Regression analysis predicting QOL in caregivers

Predictor variable	BPAD group			Schizophrenia group		
	β	t	p	β	t	p
Constant		12.397	<0.001		9.870	<0.001
Age of caregivers	-0.562	-4.570	0.001	-0.328	-3.157	0.002
Duration caregiving	-0.129	-1.199	0.234	-0.655	-2.059	0.042
Caregiver burden	-0.417	-4.923	0.001	-0.271	-2.712	0.008
HADS Depression	-0.268	-2.920	0.004	-0.254	-2.634	0.010
Patients' gender	- 0.357	3.683	0.001	-0.039	-.382	0.703
Illness duration	-0.196	-1.418	0.159	- 0.708	2.270	0.026
No of admissions	0.039	0.485	0.629	0.15	1.631	0.106
Adjusted R^2			0.561			0.306

The WHOQOL-BREF global facet of Overall perception of quality of life was the dependent variable

Longer duration of Illness and caregiving experience was associated with lower QOL scores on physical and psychological health, and environment domains.

High levels of caregiver burden was associated with deficits of QOL in the psychological, social and environment domains.

Caring for an employed patient correlated positively with physical health domain of caregivers. Being an employed caregiver did not correlate with any of the QOL BREF domains.

Caregiver physical health was inversely correlated with unmarried status of patients. Married caregivers had deficits of QOL in the psychological health, social relationships and environment domains.

High levels of anxiety and depression symptoms had similarly inverse correlation with QOL in psychological health, social relationships and environment domains.

Multiple Regression Analysis

Multiple regression analyses were conducted ondata from BPAD and schizophrenia caregivers and patients with caregiver perception of overall quality of life scores taken as the dependent variable. Caregiver's age, duration of caregiving, caregiver burden scores and the HADS depressive symptom scores were entered as independents, together with some patient variables such as illness duration, number of hospital admissions and gender. The results are presented in Table 4.

For the caregivers of BPAD patients, a strong relationship between predictors and scores in the WHOQOL-BREF quality of life measure was found, and the model explained 56.1% (adjusted R^2) of the variance in caregivers' low QOL scores[$F(7.92)=19.06$, $p<0.001$]. For the caregivers of schizophrenia patients, a strong relationship was also found between predictors and low quality of life scores , but the model explained just 30.6% (adjusted R^2)of the variance in caregivers' low quality of life scores[$F(7.92) = 7.17$, $p<0.001$].

DISCUSSION

Our results show broadly similar findings to those of previous studies on such caregiver groups. Caregiver burden levels in schizophrenia relatives have been found to be significantly greater than those of their BPAD counterparts inprevious reports (Chakrabarti and Gill 2002)

Caregiver QOL was significantly lower in the schizophrenia group than in the BPAD group. The highly significant negative correlations between caregiver QOL and caregiver burden in both groups of caregivers highlight the burdensome effects of this task on the families of mentally ill individuals. Our findings of poor quality of life, high caregiver burden levels and significant negative associations between quality of life and burden in schizophrenia relatives had been noted in many previous studies (Zahid and Ohaeri 2010, Awadalla et al 2005, Li et al. 2005).

The two patient groups and their caregiving family members were almost evenly matched on demographic variables, except that there were more female BPAD patients, and older caregivers in the schizophrenia group.The schizophrenia group had more parent caregivers and longer duration of caregiving, but the BPAD group had a longer duration of illness. Patients in both groups were more likely to remain unmarried and unemployed.

The caregivers in the BPAD group had significantly higher levels of depressive symptoms than their schizophrenia counterparts. This was an unexpected finding in our study. The contribution of caregiver depression to poor caregiver quality of life is reinforced by our findings of significant negative correlations between caregiver depressive symptoms and QOL in both caregiver groups, especially in the BPAD group. The relationship between high levels of caregiving strain and clinical depression in caregivers of mentally ill patients has been noted in many previous studies (Perlick et al. 2012, Coyne et al. 1987, Dyck et al. 1999)

Even though the pattern of negative associations between the two groups of caregivers did not show marked differences, some observations are noteworthy. For example, depressive symptoms and caregiver burden had more inverse associations with QOL in the BPAD group than in the schizophrenia group. Employed caregivers in the BPAD group had deficits in QOL, whereas no association was seen in the schizophrenia group. Older aged caregivers experienced more deficits in QOL in the schizophrenia group, than in the BPAD group. Ourfindings of a perceived reduction of QOL with advancing age of caregivers is similar to that of Ndikuno et al. (2016), in a Ugandan study on caregivers of patients with severe mental illness.

Analysis of intergroup comparisons showed that for caregivers of patients with BPAD and schizophrenia, WHOQOL-BREF domain mean scores of social relationships and environment were similar and significant difference was not found between levels of burden when the category "effects on physical health of other family members" were compared. The mean HADS anxiety symptom scores for both groups were also similar.

Multiple Regression Analyses as predicted, older caregiver age, increasing levels of caregiver burden and increasing levels of depressive symptoms in caregivers was associated with lower QOL scores in the two caregiver groups. The association between these parameters and low caregiver QOL scores supports the findings of previous research highlighting the significance of these variables as predictors of deficits in caregiver quality of life (Zendjidjian et al. 2012,Caqueo-Urizar et al. 2009). For the BPAD group, there was an association between patient gender and low quality of life scores in caregivers. It is possible that some element of bias may have influenced this association, since 81% of patients in the BPAD group were females, thus outnumbering males with a ratio of four to one. The strong association between illness duration and low quality of life scores in schizophrenia caregivers is however supported by the findings of previous research (Mitsonis et al. 2012).

In conclusion, the findings of this study support those of previous work, indicating that both disorders have similar negative impact on the family, indicating the need for caregiver support for these caregiving relatives (Zhou et al. 2016). There is a need for a longitudinal and multi-centre study with larger number of participants.

Limitations of the Study

This study had limitations in having a cross-sectional design and non blinded assessments.

Caregivers were not subjected to structured clinical interviews, and the symptoms of the patients were not evaluated with clinical assessment scales. Confounding effects of other variables such as caregiver personality was not explored. Previous reports have shown that symptoms of schizophrenia may give rise to high levels of burden in family caregivers of schizophrenia patients, and mixed episodes, rapid cycling and the number of manic episodes may also increase the severity of burden in the caregivers of BPAD patients (Ukpong 2012, Erten et al. 2014). It is plausible that patient symptomatology and number of episodes of illness could have contributed to poor QOL in these caregivers in addition to the other unexplored variables, even though the study protocol focused on caregivers of patients who were clinically stable.

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