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Towards caring for caregivers: assessing the burden of care and experience of associative stigma among caregivers of patients with chronic mental illnesses at a mental health care facility in Lagos Metropolis, Nigeria

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A – Study Design, B – Data Collection, C – Statistical Analysis, D – Data Interpretation, E – Manuscript Preparation, F – Literature Search, G - Funds Collection

Summary Background. Mental illness is becoming an inevitable part of life with an estimation of over 150 million cases occurring worldwide, commencing as early as age 15 and leading to disability and impairments. Caring for patients with chronic mental illnesses is increasingly becoming an unending fastidious task. The goal, which is often to help improve functioning and relieve symptoms, often places many demands and eventually leads to some form of burdensome experiences for the caregivers. The magnitude of this problem among caregivers, however, remains largely unknown in sub-Saharan Africa.

Objectives. The study sought to describe the level and correlation of the burden experienced by caregivers in the families of patients with chronic mental illnesses, to determine the relationship between family functioning and the level of caregiver burden and, lastly, to determine the prevalence of stigma by association/family stigma in the study population.

Material and methods. A total of 402 family caregivers of patients with chronic mental illnesses attending the outpatient clinics of the Federal Neuro-psychiatric Hospital, Yaba, were interviewed using a socio-demographic data collection sheet, family functioning (APGAR) scale, the Zarit Burden Interview (ZBI) instrument and questions measuring the psychological effects of being a relative of a patient with severe mental illness.

Results. The results of the study showed that 42% of the subjects experienced a high level of burden, and this was significantly associated with the gender of caregivers, their level of education, familial relationship of the caregivers to the patients, income, distance of residence from a health facility, family functioning and experience of family stigma.

Conclusions. Chronic mental illnesses are associated with a high level of caregiver burden in nearly half of the study population. A low level of income is an important predictor of high burden that could be addressed through occupational rehabilitation of patients and provision of employment with a view to improving family income. Introduction of support groups and continuous advocacy against stigmatisation of individuals with mental illnesses and their families are essential.

Key words: mental illness, family, caregivers, burden, stigma.

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# **Background**

Rendering care, assistance, support and aid all connote the term 'care giving' to individuals unable to function independently due to some form of impairments/disability or the other. Care giving is an on-going process, which involves the caregiver performing duties routinely, as he/she has taken the sole responsibility of ensuring that the fundamental activities of the individual in need of care are met [1]. Often times, care giving is informal, causing the provision of care to often fall within the family. The family, with its strong bonds, remains the basic unit of every society; a social and intimate nurturing group of individuals connected biologically, legally or by choice, from whom one expects a measure of support in the form of food, shelter, clothing, finance, emotional and natural nurturement, as well as sharing a past, present and future together [2].

With an increase in the incidence of mental illnesses and in the demand for care and maintenance, there is greater emphasis on community-based care. This has led to more emphasis on family management and replacing the employment of mental health institutions both in developed and developing countries. The family is now being highly recognised as a critical partner in the care of the mentally ill. However, the issue remains that family members are often burdened by the demands of caring for a mentally ill relative [3-5].

Chronic mental illness is defined by conditions such as schizophrenia, affective disorders, dementia and others (anxiety disorders, puerperal psychosis, mental and behavioural disorders secondary to psychoactive substance use, eating disorders, etc.) [6]. These conditions often lead to impairments and disability, as the mental disorder affects the brain. They occur frequently all over the world today, as early as age 15, and for which there is no certain cause and no cure except for effective treatment to ameliorate symptoms and improve functioning [7]. Its victim becomes dependent, bringing about some form of burden upon their caregivers. Although many families show tremendous resilience in caring for an ill relative, their share of physical and emotional distress cannot be ignored [7].

The term 'burden' explains the impact of a patient's behaviour upon his/her family, household and significant others, i.e. the potentially harmful effect upon the patient's caregivers. It describes the term 'family burden' or 'caregiver burden'; therefore, it refers to the effects of the mental illness of one family member on the emotional wellbeing of other family members, as well as on the family member's use of time, finances and general living conditions. Broadly speaking, this includes physical care of the patient, compromises to the personal freedom and leisure activities of the family members, financial cost, psychological burden of stigma by association and impact on functional health [8, 9].

A stigma, which is a sign of disgrace that sets a person apart from others, connotes another form of burden borne by caregivers. It not only affects people with mental illnesses, but their families as well. A stigma describes the undesirable, deeply discrediting attributes that disqualify one from full social acceptance and motivates efforts by the stigmatised individual to hide this mark when possible. Courtesy stigma or associative stigma or stigma by association are terms which describe the stigma experienced by caregivers [10]. Stigma is a well-documented consequence for the caregiver [8]. Aggressive behaviour and misbehaviour in public have been demonstrated as common sources of stress, constituting some form of embarrassment and a mark of shame on the primary caregiver [8].

In day-to-day practice, Family Physicians are likely to see patients who serve as caregivers. In fact, one study of patients in a family practice setting demonstrated that 21% of the patients held care-giving responsibilities for individuals with chronic conditions [11].

The social and economic benefits of reducing the amount of caregiver burden are enormous. Multiple studies have shown that the incidence of depression in caregivers is high, ranging from 18 to 47%, and caregivers who are depressed experience higher degrees of burden [8]. An increased incidence of anxiety corresponds to a higher amount of psychotropic drug use among caregivers.

Family caregivers have been described as forgotten or hidden patients, and it was suggested that caregivers' symptoms, such as mood swings, headache, joint and muscle pain, marital and family conflicts and financial problems, may be a reflection of the caregiver's stress in looking after a sick relative [12].

The relationships between psychological factors related to stigma or family functioning have rarely been the focus of the few existing studies on this subject. This present study will extend knowledge, as it addresses the questions: What is the level of the burden of care experienced by family caregivers of patients with chronic mental illnesses? What relationships exist between caregiver burden and family functioning, as well as caregiver burden and the experience of stigma by association?

## Methods and materials

### **Methods**

**Study Design.** The study employed a cross-sectional study design.

**Study Setting.** The outpatient clinics of the Federal Neuropsychiatric Hospital, Yaba, Lagos, a public health facility owned by the Federal Government. The facility provides both inpatient and outpatient mental health services. It is situated in the Lagos Mainland Local Government Area, within the Lagos Metropolis. The hospital has inpatient facilities with 407 beds, and hundreds of outpatients are attended to weekly. The patients attending the hospital are diverse in terms of ethnic representation and socio-economic status.

**Study Population.** The study participants were family caregivers of patients with chronic mental illnesses at the study setting

Sample Size Estimation and Sampling Technique. At 95% confidence level, desired precision of 5% and a prevalence value of 0.47 for caregiver burden from a previous study [13], a minimum sample size of 383 family caregivers was derived. The availability sampling technique was utilised.

**Selection Criteria.** Consenting family caregivers or relatives identified as spouses, parents, children, siblings and others (cousins, uncles, aunts) of patients who had been on treatment for at least two years. Friends, neighbours, colleagues and formal caregivers were excluded.

#### **Materials**

Socio-demographic and clinical details of respondents were obtained using the socio-demographic characteristics' collection sheet. The items on the sheet covered information about the age, gender, level of education, relationship to the recipient of care, employment status, income, family size, location of residence and medical history of the respondent. Information about the patient included: age, gender, diagnosis, duration of illness, stable or symptom-free period and employment status.

The perceived family functioning was assessed with the family APGAR scale (A = Adaptation, P = Partnership, G = Growth, A = Affection, R = Resolve). This is a 5-item validated scale of family functioning developed to measure a family member's perception of the family function. The total score ranges from 0-10.

The burden of caregivers among relatives of patients with chronic mental illnesses was assessed using the Zarit Burden Interview, a 22-item instrument which includes the factors most frequently mentioned by caregivers as problem areas in providing care for mentally ill patients. The instrument has a possible score of 0–88, depending on the caregiver's responses. Responses are rated 0–4, based on the level of distress. The five ranges are "0 = never", "1 = rarely". "2 = sometimes", "3 = quite frequently" and "4 = nearly always". The total burden score for a participant is the sum of the scores in all the items. This tool has been validated and used in a number of studies involving caregiver burden in Nigeria [4, 9, 13, 14].

The psychological effects of being a relative of a patient with severe mental illness was measured with a set of questions designed and administered by Margaret Ostman [8] to measure stigma by association among the caregivers. The items were adapted and validated through a pilot study involving 20 family caregivers who were subsequently excluded from the actual study.

#### **Procedure for Data Collection**

Following the identification of patients with chronic mental illnesses at the outpatient clinics of the hospital, caregivers who met the selection criteria to be called family caregivers were identified and formed the study population. The author approached each caregiver to explain the study to them and to obtain consent from those who expressed willingness to participate. Questionnaires were mostly self-administered, as the majority of the respondents were educated.

### **Data Analysis**

The statistical package for social sciences (SPSS version 20) was used, and data was analysed by means of descriptive statistics. These included: frequency counts, proportions, range, mean, median and standard deviation, as appropriate. The level of probability was set at a 5% level of significance. Chi-square tests were used to test the difference between categorical variables and association in cross tabulations. Logistic regression analysis was also used to test the level of association of a dichotomous dependent variable and independent variables.

**Ethical Considerations.** Ethical approval to conduct the study was obtained from the Ethical Review Committee of the

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Federal Neuropsychiatric Hospital, Yaba, management board. Written informed consents were also obtained from the family caregivers who agreed to participate.

### Results

Four hundred and two (402) respondents who satisfied the inclusion criteria participated in the study. A response rate of 98.1% was obtained from 402 questionnaires that were returned and analysed out of a total of 410 questionnaires that were distributed.

The majority of the respondents were 40 years of age and above (77.9%). There was a preponderance of female caregivers (52.5%). Most of the respondents had secondary and tertiary education: 49.5% and 38.6%, respectively, while a minority (2.7%) had no formal education. Regarding the relationship to the patients, most of the respondents were fathers (24.9%), mothers (20.4%) and spouses (21.4%). Children constituted 7.5%, while other relatives 25.8%. Christianity was the main religion (66.7%), and 32.1% of the respondents were Muslim. The majority of caregivers were employed (76.1%), with 56.2% of them earning more than ₹20,000/\$100. More than half of the respondents (55.2%) admitted that they received some form of financial support from others in caring for their chronic mentally ill relatives. More respondents had family sizes of 5 individuals and above (53.2%), and a majority of them resided in Lagos (95.3%).

On the part of the patients, the majority of them were males (70.6%), and most of them were above 20 years of age (87.1%). More than half of the patients (58.2%) had been stable for a year; however, a majority of them were unemployed (87.3%).

The level of burden of caregivers was measured using the Zarit Burden Interview (ZBI) scores, which ranged from 6–61

points with a mean score of 34.72 ± 0.574. The level of burden was dichotomised into low burden and high burden by using the mean score. Scores lower than mean were classified as low burden, while scores that were 34 and above were classified as high burden. A total of 168 respondents (42%) experienced a high level of burden. The mean scores and standard deviation (SD) of items in the ZBI instrument, from the highest to lowest mean score, are depicted in Table 1. The items with the highest mean scores from the ZBI instrument (items 8 and 22 with mean scores of 3.45 and 3.15, respectively) signified that the majority of respondents felt that their relatives depended upon them to a large extent, and this accounted for the feeling of burden that they experienced. In spite of this, only a minority of the respondents felt that their health had suffered because of care giving or that they had lost control of their lives since their relative's illness, as depicted by the items with the lowest mean scores (items 10 and 17 with mean scores of 2.09 and 1.69, respectively).

Table 2 shows the level of the burden of care with respect to their socio-demographic characteristics. It revealed that females accounted for 67.3% of those with high burden. Over 90% of respondents who reported a low level of burden had secondary and tertiary education. A high level of burden was also observed among mothers and spouses (35.1% and 33.9%, respectively). The majority of those with low burden earned above \$20,000/\$125 (59.8%), while 56.8% of those earning less than \$10,000/\$62.50 experienced a high level of burden, with a statistically significant difference based on level of income (p-value = 0.003). More than half of those of the Muslim faith (55.8%) experienced a high level of burden. Of the respondents residing outside Lagos, 78.9% experienced a high level of burden. The differences across religion and location of residence were statistically significant (p-values < 0.001 and 0.002, respectively).

Table 1. Mean scores and standard deviations of items in the ZBI instrument						
	Mean score	SD				
8. Do you feel your relative is dependent upon you?	3.45	1.188				
22. Overall, how burdened do you feel in caring for your relative?	3.15	1.217				
14. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend upon?	3.06	1.273				
20. Do you feel you should be doing more for your relative?	2.98	1.163				
21. Do you feel you could do a better job in caring for your relative?	2.86	1.288				
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	2.85	1.111				
7. Are you afraid of what the future holds for your relative?	2.78	1.259				
1. Do you feel that your relative asks for more help than he/she needs?	2.77	1.269				
2. Do you feel that because of the time you spend with your relative, you don't have enough time for yourself?	2.77	1.090				
4. Do you feel embarrassed by your relative's behaviour?	2.70	0.998				
13. Do you feel uncomfortable having friends over because of your relative?	2.53	1.211				
16. Do you feel that you will be unable to take care of your relative much longer?	2.49	1.473				
19. Do you feel uncertain about what to do concerning your relative?	2.46	1.099				
9. Do you feel stressed when you are around your relative?	2.45	1.169				
15. Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?	2.39	1.202				
18. Do you wish you could leave the care of your relative to someone else?	2.33	1.282				
6. Do you feel that your relative currently affects your relationships with other family members or friends in a negative way?	2.31	1.080				
5. Do you feel angry when you are around your relative?	2.30	0.954				
12. Do you feel that your social life has suffered because you are caring for your relative?	2.23	1.255				
11. Do you feel that you don't have as much privacy as you would like because of your relative?	2.17	1.179				
10. Do you feel your health has suffered because of your involvement with your relative?	2.09	1.009				
17. Do you feel that you have lost control of your life since your relative's illness?	1.69	1.097				

	Low burden	%	haracteristics of caregivers			
		<b>%</b>	High burden	%	Chi-square	р
Total	234		168		04.000	
Gender	100	50.4		20.7	24.255	< 0.001
Male	136	58.1	55	32.7		
Female .	98	41.9	113	67.3		
Age					3.512	0.061
Less than 40 years of age	60	25.6	29	17.3		
40 years of age and above	174	74.4	139	82.7		
Level of education					19.353	< 0.001
No formal education	9	3.8	2	1.2		
Primary	10	4.3	27	16.1		
Secondary	116	49.6	83	49.4		
Tertiary	99	42.3	56	33.3		
Relationship to patient					89.292	< 0.001
Father	80	34.2	20	11.9		
Mother	23	9.8	59	35.1		
Spouse	29	12.4	57	33.9		
Child	24	10.3	6	3.6		
Other	78	33.3	26	15.5		
Employment status					0.000	1.000;
Employed	178	76.1	128	76.2		
Unemployed	56	23.9	40	23.8		
Income					11.882	0.003
Less than ₩10,000/\$62.50	41	17.5	54	32.1		
<b>₩</b> 10,000 – <b>₩</b> 20,000	53	22.6	28	16.7		
Above ₦20,000/\$125	140	59.8	86	51.2		
Family size					1.446	0.229
Less than 5	103	44.0	85	50.6		
Above 5	131	56.0	83	49.4		
Family history					0.821	0.349
Marital conflict	14	15.2	7	9.3		
Family conflict	78	84.8	68	90.7		
Duration of relationship (Years)					1.042	0.791
0–19	97	41.5	70	42.9		
20–39	124	53.0	84	51.5		
40–59	12	5.1	7	4.3		
60+	1	0.4	2	1.2		
Financial support	-   -				0.214	0.643
Yes	132	56.4	90	53.6	0.22	
No	192	43.6	78	46.4		
Religion	132	+3.0	,,,	70.7	16.647	< 0.001
Christianity	175	74.8	93	55.4	10.047	\ 0.00I
Islam	57	24.4	72	42.9		
Other	2	0.9	3	1.8		
		0.9	3	1.0	0.773	0.003
Location of residence	220	00.2	153	01.1	9.772	0.002
Within Lagos	230	98.3	153	91.1		
Outside Lagos	4	1.7	15	8.9		

Figure 1 presents respondents' perception of their family functioning. The mean APGAR score was 6.99  $\pm$  0.096 points. More than half (57%) rated their families as functional.

Table 3 shows the relationship between family functioning and level of burden. Of the respondents with a high level of burden, 64.3% were from functional families (64.3%). The difference in level of burden in relation to family functioning was statistically significant (p-value = 0.032). Table 4 presents the relationship between the level of burden and the experience

of stigma. The experience of stigma was reported in 75.6% of those with high burden.

It was also discovered that approximately three-quarters (74%) of the respondents experienced stigma due to their association with patients with chronic mental illnesses, as shown in Figure 2. The experience of stigma was more pronounced among fathers (31.5%) and spouses (22.1%) than other relatives. A high level of burden was observed among those subjects that reported an experience of stigma (75.6%).

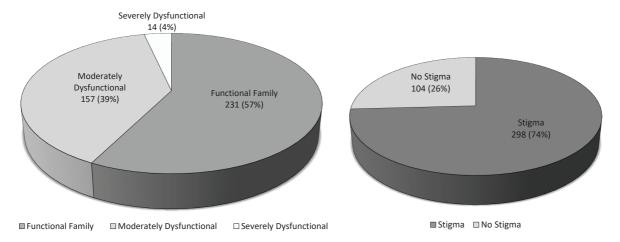


Figure 1. Perception of family functioning

Figure 2. Perception of stigma among caregivers

Table 3. Distribution of respondents' level of burden and perceived family functioning									
	Total	%	Low burden	%	High burden	%	Chi-square	p	
Total	402		234		168		6.891	0.032	
Functional Family	231	57.5	123	52.6	108	64.3			
Moderately Dysfunctional	157	39.1	104	44.4	53	31.5			
Severely Dysfunctional	14	3.5	7	3.0	7	4.2			

Table 4. Level of burden by experience of stigma								
	Low burden	%	High burden	%	Chi-square	р		
Total	234		168		0.323	< 0.001		
Stigma	171	73.1	127	75.6				
No Stigma	63	26.9	41	24.4				

# Discussion

The study shows statistically significant relationships between caregiver burden and gender of caregivers, their level of education, familial relationship of the caregivers to the patients, level of income, distance of residence from the health facility, family functioning and the experience of family stigma. In Nigeria, reports exist that caregivers of patients with schizophrenia are stressed while caring for their relatives, and that high burden was associated with large family size [13], living in the rural areas [13, 14], severity of patients' illness and caregivers' low level of education [14].

The majority of family caregivers (66.7%) in this study were fathers, mothers and spouses. This agrees with the findings from a study conducted in Northern Nigeria in 2010, which revealed that most of the care giving family members of patients with epilepsy were parents (62.7%) or spouses (17.7%) [9]. Spouses had a high degree of burden (33.9%), which is statistically significant across the other levels of relationship to the patients (p-value < 0.001).

Only a small percentage of the caregivers were children (7.2%). This may be due to the fact that children caregivers of parents with chronic mental illness may be involved with tending to their own nuclear families.

A high level of caregiver burden was found in 42% of respondents in this study, slightly lower though close to the proportion (47.3%) that was reported among relatives of patients with schizophrenia in Katsina, Nigeria in 2009 [13].

There was a significant difference in level of burden between male and female caregivers (*p*-value < 0.001). A high level of caregiver burden was found among female respondents (67.5%), supporting the findings from studies conducted in Chile in 2000 and in Nigeria in 2013 [15, 16]. This may be attributed to the fact that mothers appear to be the ones mainly responsible

for domestic and physical care; hence, they are more likely to report a significant level of family problems, physical problems and poor help seeking skill [17].

The difference in level of burden across levels of education was statistically significant (*p*-value < 0.001) A low level of burden was observed among respondents with secondary and tertiary education (91.9%). This observation corresponds with a report on the high level of burden among caregivers with a low level of education [18]. The pattern of distribution of the levels of education in this study is a reflection of the larger population of Lagos Metropolis. Lagos Metropolis is a part of the western region of the country with a high literacy level [19]. Respondents with secondary education (49.5%) and tertiary education (38.6%) accounted for 88.1% of all study participants. This finding is indicative of the healthcare seeking behaviour of those more educated in society.

The level of income was significantly related with the level of burden in this study, where 56.8% were low income earners. Although mental health services are offered at a lower cost in public facilities such as the study setting, service users still pay out of pocket in the absence of health insurance. It is notable that more than half of the patients (58.2%) in this study had been stable for a year; however, a majority of them were unemployed (87.3%) and could not contribute to family income.

The reason for the statistically significant difference in caregiver burden with respect to religion (p-value < 0.001) is unclear, more so because religious affiliations are generally thought to promote hope and provide succour.

Of the respondents with high burden, 64.3% were from functional families. This may be attributed to their degree of involvement and commitment to the care of their relatives with chronic mental illnesses [18].

The experience of stigma in this study was 74%. The experience of stigma was significantly pronounced among fa-

thers (31.5%), spouses (22.1%) and mothers (20.5%). This is consistent with the findings from a study which indicated that spouses were more often negatively affected in their ability to have personal relationships and more often experienced times of wishing that the patient had never been born or that they had never met. A high proportion of those who did not report an experience of stigma were from functional families (70.2%). Perhaps this is because functional families provide the sense of belonging that is needed to overcome any feeling of being discriminated against. A high level of burden was observed among the caregivers who reported an experience of stigma (75.6%), and this was statistically significant. The social stigma related to mental illness is widely recognised as a source of burden to caregivers. Not only does stigma directly increase the subjective burden, it also lowers access to social support, resources and opportunities, leading to social isolation and thus a greater objective burden. The socio-centric, shame-based culture of some, e.g. the Chinese, which emphasises family honour and dreads a "loss of face", is particularly sensitive to such stigma [20].

In addition, the notion of being "genetically tainted" or a "bad seed" raises concerns over the marriage-ability of patients and their family members, which may lead to careful guarding of the illness as a family secret, thus reducing social support [20].

#### Limitations

The level of burden reported in this study may not be fully reflective of the situation among the group with low level edu-

cation or no formal education within the general population, who are less likely to seek orthodox mental healthcare. Secondly, categorical assessment of family caregivers as primary or secondary caregivers may have been useful in determining which roles (primary or secondary caregiving) were considered more burdensome. However, the absence of these categories did not diminish the realisation of the original objectives of the study.

#### **Recommendations for future studies**

Assessment of the general health status in regards to the impact of caregiving on the physical health of caregivers is recommended for further studies.

#### **Conclusions**

The implications of this study make early identification of caregiver burden and appropriate intervention even more critical. Adequate education of members of the general public concerning mental illnesses is required in a consistent fashion in order to reduce stigma to the barest minimum. Caregivers should be assisted and counselled on coping strategies. Family income may also be improved through occupational rehabilitation of stable patients.

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