

Burden and psychological effects : caregiver experiences in a psychiatric outpatient unit in Lagos, Nigeria

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Abstract

Objective: Worldwide, research into experiences of care givers are gradually increasing and their central role in community care is being acknowledged. Caregivers experience a multidimensional range of problems, often associated with their caregiving role. It becomes important to identify these areas of burden and provide necessary support. The study sought to determine the prevalence of psychological distress and experience of burden of care among the caregivers of mentally ill patients. **Method:** A cross sectional descriptive study. Eligible consecutive subjects were recruited to the study over a 6 month period. Fifty three caregiver relatives of patients diagnosed with a psychiatric illness were assessed using the General Health questionnaire version 12, an Adapted Burden of Care (BOC) Schedule and a Sociodemographic questionnaire. **Results:** The caregivers were 51% male and 49% female. Most were above 35years in age (66.1%). They were either parents (38.8%), siblings (18.4%), uncle/aunt (14.3%), first cousin (12.2%) or other extended relatives (16.3%). Almost half of the relatives had psychological distress (43.8%) and most of which (63%) had more burden. The mean score on the BOC among the caregivers was 41 ($\pm 18.68SD$), with scores ranging from 0.00-89.00, and 45.3% of relatives experiencing more than average burden of care. **Conclusion:** There is a significant level of burden and psychological distress experienced by caregivers in this study location. It is recommended that effectively planned interventions are targeted at alleviating this burden and at improving the ability of caregivers to cope, within the Nigerian mental health service delivery system.

Key Words: Caregiver; Burden; Patients; Psychiatry; Nigeria

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Introduction

Worldwide in the field of mental health care, there is a shift towards encouraging community care of psychiatric patients. Caregivers - like family members or other relatives - are central to this practice most especially in Africa where the extended family system provides most of the social and economic support needed for ill patients.¹ Psychiatric illness has a major impact on both patients and their relatives.^{2,3} Care giving on its own comes with several challenges and occasional distress, as the role of caring affects every aspect of the caregivers' life⁴, with this consequence formally known as "caregiver burden". Caregiver burden is complex and has

been found to include several areas such as activities in daily life, worry and social strain.⁵

The concept of burden of care was defined by SH Zarit in 1980.⁶ Over time interest has increased in the study of burden of care and the development of various scales used in its measure.⁷⁻¹⁰ Most studies in the area of caregiver burden have focused on caring for elderly patients with brain degenerating conditions like the dementias.¹¹ However more recently studies have examined the burden experienced among caregivers of persons with severe mental disorders, like Schizophrenia.^{12,13} Researchers have recommended that clinicians need to have an approach that focuses not only on the patient but also on the parents/caregivers, as caregiving has significant influence on the overall quality of life of the caregiver.¹³

In Nigeria, Jude Ohaeri found that among Nigerian patients with schizophrenia and affective disorders the perceived support from their extended family negatively correlated with their duration of illness.¹⁴

Burden can be defined as the presence of problems,

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difficulties or adverse effects which affect the lives of psychiatric patients carers e.g members of house hold or family.¹⁵ Caregivers of mentally ill patients experience both subjective and objective types of burden.¹⁶ Subjective burdens refer to psychological consequences on the family such as the relatives' personal appraisal of the situation, and its perceived severity. Objective burden refers to outwardly measurable demands placed on family members. These include financial difficulties, strain on interpersonal relationships, a reduction in social support, physical violence, disruption of routines in carers and in households of relatives as well as leisure time. The role of caregiving can be associated with negative experiences which can be called caregiving distress; these experiences include: stigma, worry, shame, guilt but also some positive aspects which are caregiver rewards like social support and benefits given in certain societies.¹⁶ These carers have been found to worry a lot about the display of difficult behaviours, negative symptoms, attempts of patients to harm themselves and concern if the caregiver had done anything that may have made the patient ill.¹⁷ Some studies have shown that approximately one third of caring relatives have elevated levels of anxiety or depression connected with the caring role.^{18,19}

While caregiving appraisals may impact the burden of caregiving, these appraisals are often influenced by several factors, i.e. education, employment or global assessment of functioning of the caregiver.¹² Negative caregiving appraisals have been associated with caregiving distress.²⁰ In the West it has been observed that the use of practical coping strategies by relatives assist them in coping with the effects of psychiatric illness on the family.¹⁷ It has also been shown that by measuring caregivers burden, one can enhance health workers and administrator awareness of the need to reduce such burden in the health care field in general.²¹

In Nigeria, the practice of Psychiatry has evolved over several years spanning from an era of purely traditional practices and beliefs to the modern therapeutic practise of using medications and other therapies.²² However, cultural views and superstition about mental illness persist in many parts of the country and still affect care of the mentally ill, and by extension also affect the caregiver. Very limited research has been conducted locally on this subject^{23,24,25}, and this study will hopefully add to efforts in this area. The investigator's main purpose in the study was to determine the psychological factors, distress and the experience of burden of care among caregivers with the aim of contributing towards planning relevant culturally sensitive interventions to improve the wellbeing of caregivers.

Method

Location

The study location was the psychiatric outpatient clinic of Lagos University Teaching Hospital in Lagos, South-Western Nigeria. The center is a tertiary health facility receiving referrals from primary and secondary health care providers around the city. The clinic attends to an average of 100 existing and new patients per week, and at least 8-10 of them attend with a family member. Case records revealed that many of the patients attend the clinic for follow up treatment having been diagnosed with some form of mental illness in the past.

Subjects

Eligible caregivers were identified while accompanying their mentally ill relative to the clinic. To be an eligible caregiver, the person was to be over 18 years of age and to have had close contact with the mentally ill relative. The caregiver must also have been supportive either emotionally or financially to the mentally ill patient over a minimum of 6 months. In addition the patient of the recruited caregiver was expected to have been a patient of the unit for over two years, to have a working diagnosis in conformity with the ICD 10 criteria, and to not have had a diagnosis of any other chronic medical comorbidity like diabetes, hypertension in the past. This was confirmed by a detailed clinical enquiry.

Procedures

Ethical approval was sought and obtained from the Hospital Research and Ethical Committee (Lagos University Teaching Hospital). Individual participants gave informed consent before being enrolled to the research. Fifty three caregivers were enrolled to the study using consecutive patient sampling. The eligible caregivers were assigned consecutively to be interviewed by researchers on the study days, and an average of 3 to 5 caregivers were interviewed per week. Caregivers were assessed using semi-structured questionnaires. Interviews lasted between 40 minutes to 1 hour.

Measurements

Socio demographic questionnaire

A socio demographic questionnaire was designed for this study. Items in the questionnaire included: age, marital status, occupation, ethnicity, diagnosis of patient and hours spent with patient. There was also a section that enquired into the psychosocial experiences related to the caregiving role. These questionnaires were used after having been pre tested on randomly selected subjects for clarity with relevant adjustments made.

Burden of Care (BOC) Schedule

For assessing the burden of care an adapted Burden of Care Schedule (BOC) was used. The instrument was initially designed and used in a family participatory study in Israel.²¹ It was adapted for use in this environment after being back translated from English to Yoruba (a local dialect) and back to English. In preparation for its use in this study it was also administered on a separate group of care givers to determine the face validity and other psychometric properties in its use in this environment. The face validity of the BOC schedule was found to be good. The internal consistency of the instrument was determined using Nigerian samples; cronbach alpha and split-half reliabilities were computed. A cronbach alpha of .91 and a split-half coefficient of .82 were obtained. The instrument has a strong internal consistency thereby suggesting that it is highly reliable. The total burden score for each participant was the sum of scores on all the items. The mean score among all the subjects was taken as the reference point to indicate average burden of caregiving. Scores greater than the mean score were rated as more than average burden. Any score of 2 and above on each item also suggested that subjects experienced some burden in that aspect of caregiving. Psychological experiences associated with the role of caregiving were assessed using similar questions as in earlier studies.^{27,28}

General Health Questionnaire-12.

The General Health Questionnaire version 12 (GHQ-12) was used to screen for probable psychiatric morbidity in the subjects.²⁹ It was designed as a self-administered screening instrument, sensitive to the presence of psychiatric disorders in individuals presenting in primary care settings and nonpsychiatric clinical settings. It has been used extensively by several authors locally. Although most of its use was among primary care and general population subjects, it has also been found useful also in screening other special groups for psychiatric morbidity.^{31,32} The GHQ-12 has been found to be a reliable screening tool in this environment.^{32,33,34} Scores of 2 and above on the GHQ 12 were suggestive of psychiatric morbidity.

Statistical analysis

All data collected were coded and analysed using the Statistical Package for Social Sciences (SPSS) Version 17.³⁵ Frequencies and percentages were calculated for categorical variables while means and standard deviations were calculated for continuous variables. Correlational analysis was also conducted between socio-demographic variables and the raw BOC scores. The level of statistical significance was set at 0.05.

Results**BOC severity and mean scores (Table I)**

There were 53 relatives in this study. The mean total BOC score among these relatives, was 41 ($\pm 18.65D$). Twenty nine persons (54.7%) scored 41 and below. While 24 (45.3%)

Table I: Burden of care assessment

Table I: Burden of care assessment		
<i>A. AMOUNT OF BURDEN</i>	<i>n</i>	<i>%</i>
Less than average burden (= or <41)	29	54.7
More than average burden (> 42)	24	45.3
Total	53	100
<i>B. SEVERITY OF BURDEN</i>	<i>n</i>	<i>%</i>
No more than average (= or < 41)	29	54.7
Mild amount of burden (42-47)	6	11.3
Moderate amount of burden (48-53)	7	13.2
Severe amount of burden (54-59)	6	11.3
Profound burden (60 and above)	5	9.4
Total	53	100
<i>C. MEAN SCORES ON BURDEN ITEMS (score range 1 -4)</i> <i>Items (all referring to burden due to caregiver role). MIFM = mentally ill family member.</i>	<i>Mean</i>	<i>Standard deviation</i>
I am spending most of my time taking care of my MIFM	2.5625	1.04995
I am spending a lot of money on my MIFM	2.5714	1.11803
I put physical efforts into the care for my MIFM	2.7755**	1.04613
I am busy always with the care for my MIFM	2.4167	1.06857
I fall sick because of caring for my MIFM	1.4792	0.77156
I am in danger because of the attention care I am giving to my MIFM	1.2292**	0.59213
I have no time for myself because of the care of my MIFM	1.5417	0.74258
I have lost valuable time because of my care for my MIFM	1.8085	0.99211
I have less time for leisure / recreation because of the care for my MIFM	1.8776	0.9494
I no time for rest because of the care of my MIFM	1.6531	0.94761
I have no friends because of my care for my MIFM	1.375	0.78889
My plans have changed because of caring for my MIFM	1.7959	1.07973
I have no helping hand in caring for my MIFM	1.5918	0.97721
I can't tell anyone my agonizing experience with my MIFM	1.6739	0.94409
I am angry because of the care I have to give to my MIFM	1.3469	0.75142
The case of the mentally ill person in my family makes me feel over whelmed	1.4468	0.77484
I feel ashamed because of my MIFM	1.375	0.70334
I feel sad because of my MIFM	1.8776	0.9711
I get worried because of my MIFM	1.9796	0.92398
I feel embarrassed because of my MIFM	1.5625	0.84818
I am very tired because of my MIFM	1.5102	0.7671
I am afraid because of my MIFM	1.4255	0.85325
I always feel guilty because of my MIFM	1.2979	0.74934
I feel people cheat me because of my MIFM	1.3542	0.78522
People do not understand me because of my MIFM	1.5102	0.89262
I am suffering because of the burden of my MIFM	1.4898	0.84465
I have suffered this burden since last year until last month	1.8696	1.86915

experienced a burden of care that was more than average (i.e. > 41). A further categorization into 4 equal groups among those with higher scores, indicated that 9.4% of the relatives had a profound level of burden of care.

The mean scores on the individual items of the BOC Schedule ranged between 1-4. (lowest scores = 1 and highest scores = 4). The highest mean score was found on the item describing 'putting physical efforts' with 2.7755 (± 1.046) and the lowest mean score was on the item of 'feeling in danger' 1.2292 (± 0.5921).

Socio demographics and relationship with patient (Table II)

Of the 53 relatives enrolled, most were above 35 years of age (66.1%), with 27 (51%) males and 26 (49%) females. Relatives accompanying patients were mainly: parents (38.8%), siblings (18.4%), uncle/aunt (14.3%), 1st cousins (12.2%) and extended relatives (16.3%). The majority (94.2%) were in some form of employment and 79.2% rated themselves as belonging to a medium socio economic earning level of approximately 100 – 200 USD equivalent per month.

Over half of the male relatives (54.2%) had more than average

Table II : Sociodemographic profile of Caregivers and relationship to Patient

	Burden of care scores			Test
	Less than average burden	More than average burden	Total	
CAREGIVER FACTORS				
Age Group				
15-25	2 (6.9%)	8 (8.3%)	4 (7.5%)	$X^2 = 6.013, p = 0.198, df = 4$
26-35	8 (27.6%)	6 (25.0%)	14 (26.4%)	
36-45	10 (34.5%)	8 (33.3%)	18 (34.0%)	
46-55	0 (.0%)	4 (16.7%)	4 (7.5%)	
Above 56	9 (31.0%)	4 (16.7%)	13 (24.5%)	
Total	29 (100.0%)	24 (100.0%)	53 (100.0%)	
Socioeconomic level				
Low < 100 USD per mth	4 (16.0%)	3 (13.0%)	7 (14.6%)	$X^2 = 3.170, p = 0.366, df = 3$
Medium 100 - 1000 USD / mth	18 (72.0%)	20 (87.0%)	38 (79.2%)	
High > 1000 USD per mth	3 (12.0%)	0 (.0%)	3 (6.5%)	
Total	25 (100.0%)	23 (100.0%)	48 (100.0%)	
Gender				
Male	14 (48.1%)	13 (54.2%)	27 (51.0%)	$X^2 = 0.184, p = 0.668, df = 1$
Female	15 (51.9%)	11 (45.8%)	26 (49.0%)	
Total	29 (100.0%)	24 (100.0%)	53 (100.0%)	
Occupation				
Unemployed	2 (6.9%)	1 (4.3%)	3 (5.8%)	$X^2 = 3.424, p = 0.331, df = 3$
Self employed	6 (20.7%)	9 (39.1%)	15 (28.8%)	
Civil servant	7 (24.1%)	2 (8.7%)	9 (17.3%)	
Private Employment	14 (48.3%)	11 (47.8%)	25 (48.1%)	
Total	29 (100.0%)	23 (100.0%)	52 (100.0%)	
PATIENT FACTORS				
Relationship to patient				
Parent	7 (26.9%)	12 (52.2%)	19 (38.8%)	$X^2 = 9.477, p = 0.050^* df = 4$
Sibling	3 (11.5%)	6 (26.1%)	9 (18.4%)	
Uncle/Aunt	4 (15.4%)	3 (13.0%)	7 (14.3%)	
Cousin	5 (19.2%)	1 (4.3%)	6 (12.2%)	
spouse	7 (26.9%)	1 (4.3%)	8 (16.3%)	
Total	26 (100%)	23 (100%)	49 (100%)	
Patients Diagnosis				
Schizophrenia	13 (44.8%)	7 (29.2%)	20 (37.7%)	$X^2 = 9.633, p = 0.141 df = 6$
Bipolar affective disorder	5 (17.2%)	2 (8.3%)	7 (13.2%)	
Depression	0 (.0%)	3 (12.5%)	3 (5.7%)	
Substance abuse	1 (3.4%)	2 (8.3%)	3 (5.7%)	
Mental retardation	1 (3.4%)	1 (4.2%)	2 (3.8%)	
Complex partial seizures	0 (.0%)	3 (12.5%)	3 (5.7%)	
Others	9 (31.0%)	6 (25.0%)	15 (28.3%)	
Total	29 (100.0%)	24 (100.0%)	53 (100.0%)	

burden, but this was not statistically significant ($p = 0.668$). Over 60% of patients had a diagnosis of schizophrenia (ICD 10 diagnostic criteria) while 25% had a diagnosis of bipolar affective disorder, 6.3% had depression and 6.3% had complex partial seizure disorders. The commonest diagnosis among the patients of those relatives with more than average burden was schizophrenia (57.1%) ($p = 0.407$).

Relatives in this study spent on average 9 (± 11) hours per day with the patient and 39 (± 35) hours per week. The caregivers with more than average burden spent over 11 hours (± 14 hrs) per day while those with no more than average spent about 6 hours (± 5 hrs) per day with the patient. This was not however statistically significant using the paired t test ($p = 0.128$; t test = -1.557)

Correlating the number of hours spent with the burden of care scores using the Pearsons Moment Tests, the BOC scores correlated significantly with the GHQ with a correlation coefficient of 0.52 ($p = 0.00$).

Psychological factors and care giving (Table III)

Almost half of the relatives had some degree of psychological distress i.e. 43.8% ($n= 21$), and 63.6% ($n=14$) had more than average experience of burden, which was statistically significant ($p = 0.011$).

Almost a fifth ($n= 9$, 17.0%) did not feel supported by the hospital staff and 15.1% said the illness made it impossible for them to have friends, 17% wished the patient were never born,

Table III : Psychological experiences related to caregiving

	Burden of care scores			Test
	Less than average	More than average	Total	
GHQ Group				
No Psychological Distress	19 (73.1%)	8 (36.4%)	27 (56.3%)	$X^2 = 6.527, p = 0.011^* df = 1$
Possible Psychological Distress	7 (26.9%)	14 (63.6%)	21 (43.8%)	
Total	26 (100.0%)	22 (100.0%)	48 (100.0%)	
Affects possibility of having friends				
Definitely Yes	3 (10.3%)	5 (20.8%)	8 (15.1%)	$X^2 = 1.127, p = 0.288 df = 1$
Not at all	26 (89.7%)	19 (79.2%)	45 (84.9%)	
Total	29 (100.0%)	24 (100.0%)	53 (100.0%)	
Supported on care giving burden				
Definitely Yes	21 (72.4%)	15 (62.5%)	36 (67.9%)	$X^2 = .592, p = 0.441 df = 1$
Not at all	8 (27.6%)	9 (37.5%)	17 (32.1%)	
Total	29 (100.0%)	24 (100.0%)	53 (100.0%)	
Wish Patient were never born				
Definitely Yes	3 (10.3%)	6 (25.0%)	9 (17.0%)	$X^2 = 2.001, p = 0.157 df = 1$
Not at all	26 (89.7%)	18 (75.0%)	44 (83.0%)	
Total	29 (100.0%)	24 (100.0%)	53 (100.0%)	
Care resulting in Relatives mental illness				
Definitely Yes	4 (13.8%)	7 (29.2%)	11 (20.8%)	$X^2 = 1.887, p = 0.170 df = 1$
Not at all	25 (86.2%)	17 (70.8%)	42 (79.2%)	
Total	29 (100.0%)	24 (100.0%)	53 (100.0%)	
Ever thought of suicide				
Definitely Yes	2 (6.9%)	4 (16.7%)	6 (11.3%)	$X^2 = 1.249, p = 0.264 df = 1$
Not at all	27 (93.1%)	20 (83.3%)	47 (88.7%)	
Total	29 (100.0%)	24 (100.0%)	53 (100.0%)	
Wish patient were dead				
Definitely Yes	4 (13.8%)	6 (25.0%)	10 (18.9%)	$X^2 = 1.077, p = 0.299 df = 1$
Not at all	25 (86.2%)	18 (75.0%)	43 (81.1%)	
Total	29 (100.0%)	24 (100.0%)	53 (100.0%)	
Gets Support from other family members				
Definitely Yes	18 (62.5%)	12 (50.0%)	30 (56.6%)	$X^2 = .779, p = 0.378 df = 1$
Not at all	11 (37.9%)	12 (50.0%)	23 (43.4%)	
Total	29 (100.0%)	24 (100.0%)	53 (100.0%)	
Receiving support from Staff				
Definitely yes	25 (86.2%)	19 (79.2%)	44 (83.0%)	$X^2 = .462, p = 0.497 df = 1$
not at all	4 (13.8%)	5 (20.8%)	9 (17.0%)	
Total	29 (100.0%)	24 (100.0%)	53 (100.0%)	

11.3% had thought of committing suicide and 18.9% wished the patient were dead. These groups of people represented about 17 – 25% of relatives with more than average burden of care. None of these other findings were however statistically significant.

Discussion

Burden of Care giving

Though the aspects of care giving that cause burden may be generally similar, the experiences reported by relatives are often varied, depending on the nature of the illness, and effects of different psychological factors. The current study found that the feeling of having to exert a lot physical effort was the commonest caregiving role associated with high burden, while the feeling of being in danger was the least burdensome.

Some earlier researchers had also found that the general experience of burden was moderate among most caregivers of psychiatric patients, with the feeling of being in danger being mildest and worry being most severe.³⁶ Another study also reported that more than half of the caregivers felt that their work load had increased due to illness in patient.³⁷ The slight difference in our findings may be due to the absence of adequate social support services to give some respite or relief in the caregiving effort to relatives unlike other western countries where such services exist and aid in relieving some of the burden relatives experience. The large prevalence of more than average burden among almost half of the caregivers, emphasises the importance of investigating the impact of such burden.

Psychosocial Factors in Care giving.

In this study most of the caregivers aged above 35 years experienced more than average burden. Though some studies have shown that younger caregivers had been reported to experience a higher caregiving burden¹⁴, others had found that burden is not related to age of caregiver.²¹

Commonly the female relatives engage in caregiving and have been reported as experiencing most of the associated burden.³⁸ In this study the males appeared to experience more than average burden (54.2%) than their females counterpart ($p < 0.005$). This might possibly be due to negative caregiving appraisals coming from men who traditionally are not involved in caregiving roles.

The amount of time spent in the company of the patient has also been associated with more experience of burden. Some researchers have found that relatives residing with the patient often experienced higher caregiving burden.^{39,40,41} Our study confirms this with the number of hours spent with patients being positively correlated with higher experience of burden as recorded with the score on the burden of care schedule. The current study found that parents were often the care givers of these psychiatrically patients, and most of them experienced more than average burden in their care giving role ($p = 0.05$), when compared with other relatives.

Psychological experiences in care giving

High levels of occurrence of psychological distress have been reported among relatives of people with severe mental illness.²⁷ Almost half of the caregivers in this study had psychological distress, which was statistically significant ($p = 0.011$). Of these, the majority experienced a more than average burden in the course

of their care giving role. Comparing the mean GHQ scores of those with more than average burden alongside those with average burden, it was found that those with more than average burden generally scored higher on the GHQ. This suggests higher psychological morbidity in this group and this finding was found to be significant ($p = 0.002$, $df = 46$, t test = -3.218).

Studies have consistently shown that at least one-third of caring relatives have elevated levels of anxiety or depression connected with the caring role¹⁰, and some researchers have found up to 60% of caregivers feeling very anxious and depressed.³⁷

In exploring other psychological factors faced by the caregivers in the course of fulfilling their roles, this study found more than half the relatives felt adequately supported by the staff in the facility while a quarter admitted to feeling inferior to the staff. Most of the relatives that did not feel supported had psychological distress ($p = 0.048$), and only a fifth felt the illness had affected the possibility of them having their own friends.

Similar to other studies²⁷, many relatives in this study had expressed belief that the ill relative would be better off dead and/or wished the patients had never been born. This group constituted a quarter of the relatives with more than average burden. Though this finding was not statistically significant it is noteworthy. They also admitted they had received support in their caregiving role either from family members, employees of psychiatric services or government agencies. The experience of feeling inferior to staff may suggest inadequate levels of support from the service providers at the study location.

Some researchers had earlier found that interventions that enhance problem-solving coping strategies for caregivers may relieve some psychological distress and bring about positive changes in distress burden and coping.³¹ One is hopeful that the creation and use of locally based family support organizations may also be useful in the care of these relatives.

A limitation of the study was its small sample size, hence the results may not be generalizable to all relatives of people with mental illness in the larger population.

Recommendations

Larger multicentered research is recommended to further explore the experience of caregivers along with the possible benefits from training caregivers in the use of necessary coping skills. There is also a need for increased political willpower to legislate on policies designed to meet the needs of the caregivers of mentally ill persons. Locally based family support groups should be created for assisting caregivers and advocating for the promotion of their cause in society.

Conclusion

It is evident that there is an actual burden which is significant among these caregivers. The risk of psychological distress amongst caregivers increases with this experience of burden. The ability to address these experiences will have consequences on the overall mental and physical wellbeing of the patient. Treatment approaches need to be mindful of the role of the caregiver, and the impact of illness on their wellbeing.

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