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Economic Burden and Coping Strategies of Caregivers of Children and Adolescents with Mental Illness Receiving Treatment in Hospitals in Kano State

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Abstract
Changes in family structure and drastic economic decline in Nigeria are threatening the healthcare services support available to children and adolescents with mental illnesses. The study was conducted among caregivers of children and adolescents with mental illness to find out the economic burden of care-giving to children and adolescents with mental illness and their opinion on coping strategies. Cross-sectional descriptive design was used. A total of 253 caregivers were recruited for the study using systematic random sampling technique. A structured questionnaire was adapted from Burden Interview. Data collected were organised and analysed with SPSS version 23 and results were presented using and improving the frequency distribution tables and percentages, mean and standard deviation. The study revealed that majority (35.7%) of the caregivers experienced high economic burden, (33.6%) rated the burden as moderate while 20.7% rated it as mild. Majority (25.7%) of the caregivers were of the opinion that free or subsidised health services could help in overcoming caregivers' challenges, 48 (13.9%) identified provision of social services and special schools and 13.2% mentioned skill acquisition programmes and financial support, improve coverage of National Health Insurance Scheme to all non-working class citizenry.

Keywords: *Economic Challenges, Coping Strategy, Caregivers, Mental Disorders, Children and Adolescents*

Introduction

One-third of the world's population is children and adolescents, with the majority living in low and middle-income countries (LMICs), in which, around 10 to 20 % suffer from a mental health problem (Kieling, Baker-Henningham, Belfer, Conti, Ertem, Omigbodun, *et al.,* 2011). Worldwide in the field of mental health care, caregivers are central to patient's care more especially in Africa where the extended family system provides most of the social and economic support needed for ill patients (Ndetei, Pizzo, Khasakhala, Maru, Mutiso and Ongecha-Owuor, 2009). Brodaty & Donkin (2009) stated that strains due to medical costs; missed work and patients' economic dependency are considerable and are linked to both objective and subjective burden of caregivers. Caregiving on its own comes with several challenges and occasional distress, as the role of caring affects every aspect of the caregivers' life. This consequence is formally

known as "caregiver burden" which is complex and has been found to include several areas including financial difficulties (Oshodi *et al.,* 2012). Caregiver burden in mental illness can either be objective or subjective. The objective burden includes the financial difficulties, strain on interpersonal relationships, reduction in social support, physical violence, disruption of routines in care and in households of relatives as well as leisure time, whereas the subjective burden deals with psychological consequences on the family such as the relatives' personal appraisal of the situation, and its perceived severity (Flyckt, Löthman, Jörgensen, Rylander & Koernig, 2013).

Ambikile and Outwater (2012) explained that the economic challenges that caregivers experienced were mainly due to poverty, childcare interfering with various activities such as business, and extra expenses associated with the illness. In the United Kingdom, Emerson (2003) found similar poverty challenges that were experienced by families of children with intellectual disabilities when they were compared to families without such a child.

In evaluating the financial expenditure due to the mental disorder, Buriola, Vicente, Zurita, and Marcon (2016) found that (23.3%) caregivers were very overwhelmed and more than half (57.3%) did not report increased expenses due to illness. This may be related to the fact that the psychotropic medication used by children and adolescents is provided free of charge by University Health Services. Vermeulen, Lauwers, Spruytte, Van Audenhove, Magro, Saunders, & Jones (2015) revealed that half of the caregivers (49%) worry about the financial situation of the person they care for and are concerned about the persons becoming too dependent on them in the future (55%). Families with lower socioeconomic status experienced higher level of burden (Sally, 2011). The problem of lower socioeconomic status is further compounded by the fact that most countries Nigeria inclusive do not provide financial support for the care services and that families are solely responsible for providing financial support for their mentally ill children or adolescents (World Federation of Mental Health, 2010). The poor financial status in the family may further increase the risk or vulnerability for perceiving burden and the resulting distress and negative consequences such as mental health problems. Andren and Elmstahl (2007) reported that low income was associated with a higher degree of burden on the caregivers. Low income was a stressor that influences stress feeling when providing care for an ill family member.

Families are generally vulnerable and unprepared to cope with the entire process of the illness and treatment (Kate, Grover, Kulhara, Nehra, 2013, and Cotton, McCann, Gleeson, Crisp, Murphy, Lubman, 2013). For this reason, nurses and other healthcare professionals who live with this reality have a fundamental role to play on the caregivers binomial, supporting them and helping them identify stressors, understanding and recognising how they cope with problems so as to intervene and minimise suffering, thus making a positive contribution to their readjustment (Caqueo-Urízar, Miranda-Castillo, Lemos, Lee, Ramírez, Mascayano, 2014, Seo, Byun, Park, Kim, 2012, and Margetić, Jakovljević, Furjan, Margetić, Marsanić, 2013). Thus, the study aimed to investigate the economic burden and coping strategy opinions of caregivers of children and adolescents with mental illness receiving treatment in hospitals in Kano state.

Methods and Materials

Setting: The study was carried out in two hospitals, Aminu Kano Teaching Hospital (AKTH) and Dawanau Psychiatric Hospital that offer mental healthcare services located in Kano, the capital city of Kano State in Northwestern Nigeria. Approximately 35% of the population is educated with high gender disparity in school attendance and literacy (Kano State Government, Department of Statistics, 2004). The principal inhabitants of the city are the Hausa-Fulani, although a good

number of other ethnic groups, such as the Igbos and Yorubas also inhabit parts of the city. The major language spoken is Hausa, although English is also widely spoken in schools, offices, and markets. A sizeable number of its inhabitants engage in farming, some are civil servants while the rest are largely traders.

Study Design

Cross-sectional descriptive research design was employed to find out the economic burden on the caregiver of children and adolescents with mental illness and caregivers' opinion on coping strategies.

Study Population and Sampling

The study population comprised all caregivers of in-patient and out-patient adolescents and children with mental illness in Hospitals in Kano State. The respondents were proportionately selected based on a monthly ratio of caregivers' population of 1:2 (84 and 169 respondents) for AKTH and Dawanau respectively. Systematic random sampling technique was employed for the selection of respondents and the list of all the registered patients formed the sampling frame.

A total of 253 caregivers were recruited for the study based on caregiver burden prevalence rate of 58.7% Dada *et al.,* (2011), using the formula $n=z^2pq/e^2$ (Lwanga and Lemeshow, 1991).

Research Instrument

The data was collected using adapted Burden Interview developed by Zarit, Reever and Bach-Peterson (1980) for economic burden. Completed questionnaires were checked for errors, consistency, and completeness and cleaned. A total of two (2) hospitals that render psychiatric care in Kano State were assessed and 253 caregivers participated in the study. The response rate was 95.6%.

Data Analysis

Data were analysed using Statistical Package for Social Sciences (SPSS) software version 23. The data were summarized using frequency distribution tables and percentages. Mean and standard deviation was used for continuous variables while frequencies and percentages were employed for discrete variables. The scoring for economic burden is used to grade the level of burden. The total score of the burden range from 0 - 36. The burdens were categorized as mild (0-9), moderate (10-18), high (19-27) and severe (28-36).

Ethical Approval

Ethical approval was obtained from the research ethics committee of the AKTH and Kano State Ministry of Health Research Ethics Committee of the hospitals. Written informed consent was obtained from respondents after informed about their voluntary participation, their rights to withdraw their consent at any stage of the research and on the confidentiality, purpose, risk, and benefits of the study.

Results

Caregivers' Socio-Demographic Characteristics

The findings from the study show that the majority of the caregivers (38.2%) were within the age range of 36-45 years. Mothers constituted 54.8% of the caregivers; while fathers made up the rest (31.5%). Also, most (50.2%) caregivers had no formal education, 49.8% reported being self-employed and 37.3% unemployed. Majority of them were on income of <₦10,000 (60.2%) while 27.0% were on ₦10,000-25,000 as income (see Table 1).

Table 1: Socio-Demographic Characteristics of Respondents (n= 241)

Variables	Frequency	Percentage (%)	Mean/SD
Age of caregivers			
25-35	72	29.9	
36-45	92	38.2	17.59/ 10.31
>46	77	32.0	
Designation of caregiver			
Father	76	31.5	
Mother	132	54.8	
Grandfather	2	0.8	
Grandmother	5	2.1	
Others	26	10.8	
Marital status			
Married	207	85.9	
Divorced	16	6.6	
Widow	17	7.1	
Single	1	0.4	
Religion			
Islam	218	90.5	
Christianity	23	9.5	
Educational attainment			
No formal education	121	50.2	
Primary	35	14.5	
Secondary	43	17.8	
Tertiary	42	17.4	
Occupation			
Unemployed	90	37.3	
Self-employed	120	49.8	
Government employed	29	12.0	
Private sector	2	0.8	
Income			
<₦10,000	145	60.2	
₦10,000-25,000	65	27.0	
₦26,000-40,000	18	7.5	
₦41,000-55,000	1	0.4	
>₦56,000	12	5.0	
Ethnicity			
Hausa/Fulani	216	89.6	
Igbo	16	6.6	
Yoruba	9	3.7	

Caregivers' Economic Burden

Table 2a indicates that most caregivers' economic burdens were homelessness from the sickness (50.6%), childcare negatively interferes with the economic capacity of the family (61.8%), medical bills were not affordable (69.3%), lack of organised social support (79.3%), care-giving was superimposed on an already existing poverty in the family (77.6%). This indicates that poor social support and poverty arising from the care-giving are the most distressing.

Table 2b indicates the rating of the economic burden of the caregivers: high economic burden (35.7%), moderate (33.6%) and mild (20.7%)

Caregivers' Opinion on Coping Strategies

Table 3 shows that majority (25.7%) of the caregivers were of the opinion that free or subsidised health services could help in overcoming caregivers' challenges, 58 (16.8%) mentioned seeking for treatments and adherence to medication regimens. 48 (13.9%) had the opinion of the provision of social services and special schools and only 46 (13.2%) indicated skill acquisition programmes and financial support. The findings also show that 30 (8.7%) of the caregivers mentioned societal re-orientation and re-enforcing agencies like the National Drug Law Enforcement Agency (NDLEA).

Table 2a: Economic Burden on Caregivers of Children and Adolescents with Mental Illness (n= 241)

Economic Challenges	Yes	No
Sickness rendered us homeless	122 (50.6%)	119 (49.4%)
Childcare negatively interferes with the economic capacity of the family	149 (61.8%)	92 (38.2%)
Medical bills are not affordable	167 (69.3%)	74 (30.7%)
Lack of organised social support	191 (79.3%)	50 (20.7%)
Care-giving was superimposed on an already existing poverty in the family	187 (77.6%)	54 (22.4%)

Table 2b: Grading of Economic Burden on Caregivers of Children and Adolescents with Mental Illness (n= 241)

Variables	**Frequency**	**Percentage (%)**
Mild	50	20.7
Moderate	81	33.6
High	86	35.7
Severe	24	10

Mild (0-9), Moderate (10-18), High (19-27), Severe (28-36)

Table 3: Caregivers' Opinion on Coping Strategies

Variables	**Frequency**	**Percentage (%)**
Free or subsidised health services	89	25.7
Seeking for treatments and adherence to medication	58	16.8
Provision of social services and special schools	48	13.9
Skill acquisition program and financial support	46	13.2
Societal reorientation and re-enforcing agencies like NDLEA	30	8.7
Psycho-social therapy	26	7.5
Turn to prayer/praying	25	7.2
Provision of adequate and competent staff and facilities	24	7.0

NB: There are multiple responses

Discussion of Findings

The result of this study revealed that majority of the respondents (38.2%) were within the age range of 36-45 years with a mean age of 17.59 (SD=10.31). This is not consistent with the findings of Yusuf *et al.,* (2013) in Katsina State which reported that the mean age of the caregivers was 45.44 years. Moreover, the finding was not in line with Vermeulen *et al.,* (2015) who in a study in 22 European countries reported a mean age of 58 years. Findings revealed that one in six caregivers was younger than 55 years (14%) and one third older than 65 years (33%). The caregivers' lower age in this study will likely predispose them to more burden in caring for their clients. The study also revealed more than 54.8% of caregivers are mothers while 31.5% are fathers. Women were more likely

to be caregivers based on community traditions and culture. This is consistent with Census Report (2011) in the United Kingdom, Chan *et al*., (2011) in Asian countries and World Federation of Mental Health (2010) that variously found that about 58% of the caregivers were women, and 70% of family caregivers were females, who could be the mother, wife, or daughter of the clients. The findings also showed that 50.2% of caregivers had no formal education and 14.5% had primary education. This finding may be due to the fact that in Hausa culture girls-child education were not given due consideration and the majority of the caregivers were women. The finding is also in line with the findings of AbdulMalik *et al.,* (2012) in Northern Nigeria, and Ae-Ngibise *et al.,* (2015) in rural Ghana, that reported that majority of (62.4%) caregivers did not attend any school, with 15.3% having only primary education. The study also revealed that 49.8% were self-employed, 37.3% unemployed with monthly income of <₦10,000 (60.2%) and ₦10,000-25,000 (27.0%) as income. This is attributed to the fact that most of the caregivers had no formal qualification and by implication will be unemployed or self-employed, besides, many of the respondents were married women and most of the married women in Hausa communities are complete housewives engaged in petty trading or having no source of income, which will hamper their ability to purchase drugs and pay other medical services for the clients.

The findings of the study were also inconsistent with Oshodi *et al.,* **(**2012) in Lagos, Nigeria, who reported that, most of the caregivers (94.2%) were in some forms of employment with 79.2% rating themselves as belonging to a medium socio-economic earning level of approximately 100 – 200 USD equivalents per month. The study is also in line with World Federation of Mental Health (2010), OECD (2012) which in a study in Australia, United Kingdom and United States, reported that caregivers are usually within the low-income bracket and caregivers of children and adolescents with a severe mental disorder live in households with income below the low-income threshold; the proportion is almost high in other countries including Nigeria.

The study finding also reported childcare brought about homelessness (50.6%), negative interference with the economic capacity of the family (61.8%), and superimposed poverty in the family (77.6%). These problems have the tendency of affecting caregiver's economic challenges as well as increase the burden that will be experienced from a caring role. Thus, proper time management and involvement in less committed income-generating activities will assist in overcoming such difficulties. A similar finding was reported by Ambikile *et al.,* (2012), in Muhimbili, Tanzania where it was revealed the economic challenges to include poverty, interference with various income-generating activities in the family, and extra expenses associated with the child's illness. In the United Kingdom, Emerson (2003) found similar poverty challenges, including medical bills not being affordable (69.3%), experienced by families of children with intellectual disabilities when compared with families without such a child. This calls for concern because caregivers need to meet the financial challenges for health services of their mentally ill patients but should also find modalities of managing time adequately to achieve a better and appropriate goal for caring. According to Funk *et al.,* (2012), mental disorders have diverse and far-reaching social impacts for caregivers including lack of employment and limited income-generating opportunities that could lead to homelessness.

McDaid *et al.,* (2005) buttressed the assertion that loss of (caregiver's) employment, absenteeism, poor performance within the workplace and premature retirement might result due to care-giving. Similarly, the study further revealed that lack of organised social support (79.3%), The findings from caregivers were buttressed by Ambikile *et al.,* (2012) in Dar es Salam, Tanzania, lack of social support and inadequate social services for children

with mental disorders were the most challenging issues for caregivers.

Majority of the caregivers (35.7%) experienced high (scores 41-60) economic burden, 81 (33.6%) rated the challenges as moderate while 20.7% rated it as mild (scores 0-20). This could be associated with the fact that the education level has a negative correlation with caregiver's economic burden. It was assumed that the lower the level of education, the lower the salary will be. Lower salary would increase financial problem related to providing care for the mentally ill children and adolescents. This is buttressed by Andren *et al.,* (2007) who reported that low income was associated with a higher degree of burden on the caregivers for mentally ill children and adolescents.

Sally (2011) affirmed that families with lower socio-economic status experienced a higher level of burden. Similarly, WFMH (2010) further expatiated that, the problem of lower socio-economic status is further compounded by the fact that most countries including Nigeria do not provide financial support for the care services and that families are solely responsible for providing financial support for their mentally ill children or adolescents. The poor financial status in the family may further increase the risk or vulnerability for perceiving burden and the resulting distress and negative consequences such as mental health problems.

The study report was in agreement with the findings of Ajibade *et al.,* (2016) in Ekiti State, Nigeria, which revealed that high burden, was associated with the amount of money spent while trying to meet other responsibilities. The study is however in disagreement with Panayiotopoulos *et. al.,* (2013) in Cyprus and Buriola *et al.,* (2016) in Maringa, Parana, Brazil, who reported that the financial burden was mild for the majority of the caregivers as only 15% of them reported heavy financial burden in the study. Although 63.7% of the caregivers were concerned about the harsh economic situation and found that 23.3% caregivers were experience moderate financial burden due to mental illness. This is probably due to the fact that Cyprus and Brazil as nations have good health care delivery systems that support and provide affordable and accessible services to their citizenry.

The majority (25.7%) of the caregivers were of the opinion that free or *subsidised* health services could help in overcoming caregivers' challenges,48 (13.9%) identified the provision of social services and special schools and 13.2%mentioned skill acquisition programmes and financial support. These findings revealed caregivers' harsh economic conditions and lack of social services required by caregivers of children and adolescents with mental illnesses. Thus, providing such services will reduce the burden of care-giving. The study report was in agreement with the findings of Pompeo, Carvalho, Olive, Souza, and Galera, (2016) coping strategies most often used by caregivers were social support and problem-solving approach. Sabanciogullari and Tel (2015) added that caregivers used psychological and social coping strategies.

Conclusion

Among the major economic challenges arising from care-giving found were issues of rendering families homeless, depreciating economic capacity of the family, high medical bills that are difficult to afford, lack of organised social support and poverty. Caregivers desire free or subsidised health services, adherence to medication and treatment regimens, provision of social services and special schools, skill acquisition programmes and financial support and societal re-orientation and re-enforcing agencies like NDLEA could serve as coping strategies. These are enormous bottlenecks to caregivers, family, and community in caring for child and adolescents with mental illnesses.

Recommendations

Based on the findings, to curtail economic challenges:

i. Free or subsidised health services that are available, accessible and at an affordable rate should be provided by

the government for all children and adolescents with mental illness.

ii. There is a need to improve coverage of the National Health Insurance Scheme to all non-working class citizenry especially children and adolescents with mental illness.

iii. Young people living with mental illness should be given the opportunity to be gainfully employed to help address economic burden related to their care in the future.

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