

## Family Caregivers' Knowledge about their Ill Relatives' Mental Illness and Treatment: Perspectives from the Niger Delta Region of Nigeria

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### Abstract

**Background:** Many people with mental illness rely on family and friends for support and to help them in their activities of daily living. At all points in the care of ill relatives, caregivers need information to deal with the patient's care and treatment demands.

**Methods:** This was a descriptive study carried out in a Public owned mental health out-patient clinic. The study consisted of fifty participants, who voluntarily completed a questionnaire regarding their knowledge about their ill relatives' mental illness and treatment.

**Results:** Majority (62%) were female, and (28%) were parents (66%) has primary level education, (76%) had no knowledge about illness of relatives, (84%) did not know the diagnosis (76%) had poor knowledge of medication, and (84%) could not recognize the side effects of medication.

**Conclusion:** The need for information and education of family caregivers about ill relatives' mental illness, and the important role of medication regimen in the control of symptoms of the disorders. Education on medication and other treatment strategies should be tailored towards each family caregiver's understanding and level of education.

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## Introduction

People with mental illness cannot access treatment in primary or general health care settings in Rivers State, Nigeria, and need to attend a centralized Public Psychiatric Hospital, at which all mental health care is provided. Many persons with mental illness remain at home due to the lack of adequate facilities to accommodate them, with only those who are severely affected being admitted. For those not admitted, out-patient clinics enable them access to health professionals and treatment services. This is also where discharged patients are monitored during their follow-up routine clinic appointments and for medication re-fill. This institutional model of mental health care has resulted in family members having considerable responsibility in caring for their ill relatives without the necessary knowledge, skills and support to do so [1], despite playing a crucial role in the care and recovery process [2-3].

The nuclear family members maintain and support their sick members, provide shelter, financial, emotional and spiritual support, as well as source and secure treatment [4-5]. The ill relative is often faced with isolations, and the loss of employment and friends due to myths and prejudice surrounding mental illness [6]. Evidence shows that their families social and emotional support have been found to be of considerable value and an important factor in the recovery process [7-8], with most mental health providers contending that educating families about mental illness is very important [3]. Mental health professionals should be concerned about improving communication with and education for family caregivers to ensure appropriate quality of care.

Shinde et al [9] argued that due to inadequate knowledge and care-giving skills, family caregivers may be unfamiliar with the type of care they must provide or the amount of care needed. They need a basic level of knowledge about mental illness and how to access help for ill relatives during a crisis [10]. This kind of

knowledge can facilitate a partnership with health professionals to find a treatment approach that works for their relatives [11]. Knowledge is a crucial building block to develop the skills necessary to manage symptoms outside the mental health facility. Relevant skills are important to help family caregivers maintain a healthy lifestyle, recognize early warning signs of relapse, and act promptly to manage stressful situations [2].

Many people with mental illness rely on family and friends for support, and to help them in their daily activities [12]. Family caregivers need to know the expected outcomes of the disorder, as well as challenges that may arise during transition from hospital to the home environment. Studies have shown that including families in the planning and care of ill relatives has a strong influence on mental health, even brief family involvement were reported to improve health and recovery, reduce the risk of a relapse, and increase family wellbeing [13-14]. A study [15] reported that unawareness of illness among caregivers was associated with lower use of coping strategies and frequent resignation. Mental health professionals can help families become collaborative agents in the treatment process to achieve positive treatment outcomes [16]. Evidence show the more information family caregivers have, the better they can put the illness in perspective [2,10]. This study is therefore aimed at exploring family caregivers' knowledge about mental illness and treatment of their ill relatives, and to suggest self-management program to support and enhance the care giving process.

## Method

A descriptive study carried out in a State owned mental health facility that provides both in-patients and out-patients services. The target population for the study consists of family caregivers of ill relatives, who had been admitted and then discharged but are currently attending the out-patient clinic for their routine check-up and medication re-fill at the time of this study.

The study lasted for 6 consecutive weeks in February 2015. All family caregivers who reported to the mental health outpatients' clinic; who gave informed consent and who were able to read and write in English were enrolled in the study. The study instrument was a semi-structured interview administered questionnaire. Information was sought on their socio demographic data, knowledge about relatives' mental illness, and knowledge of medication regimen. The participants were informed they could withdraw at any time, and were assured of confidentiality and anonymity. The researchers distributed the questionnaires to the participants in the waiting room and retrieved them immediately on completion. The data were analyzed using Statistical Package for Scientific Solutions (SPSS) IBM version 20. Ethical approval was obtained from the State Ministry of Health and Ethics Committee of the hospital.

## Results

### Table 1: Demographic Data of participants

Table 1 shows that, almost two third (62%) were female. Those in the age in the range between ages 34-49 (60%) accounted for majority of the participants. Majority were married (54%), with similar numbers being single, divorced and widowed. The majority (82%) were Christian and almost half (44%) were civil servant, one third (34%) were self-employed, a small percent (12%) were farmers, and (10%) were students. Regarding educational qualification, two third (66%) had primary education only, one fifth (22%) had completed secondary school, only (12%) had a tertiary education and over half (28%) were parents.

### Table 2: Family caregivers' knowledge about mental illness of ill relatives (n=50)

Table 2 show that only one quarter (24%) of family caregivers knew about the type of mental illness of their ill relatives, and only (16%) knew the correct name of the illness. Less than one third (30%) could recognize the signs of relapse. Almost all the participants

(86%) said their ill relative will get better with treatment, but only one third (66%) were satisfied with care from professionals.

### Table 3: Family caregivers' knowledge about ill relatives treatment (n=50)

Table 3 shows that only one quarter (24%) knew the name of their relatives' medication, and (16%) knew the correct medicine dosage/frequency. Half (46%) could recognize the side effects of the medicine, but only one third (34%) knew how to deal with medication side effects. Half (54%) knew that their relatives takes the medicine regularly as prescribed, and one quarter (28%) accessed information from sources other than the clinic, while for nearly three quarters (72%) the clinic staff were their only source of information.

## Discussion

Majority of the participants were female, this finding is similar to other family caregiving studies [2,17]. Majority were married and are Christians, the reason being that the Niger Delta region of Nigeria is predominantly Christian. Only 44% had regular paid employment and majority had basic level education. The finding is similar to a study [13] that reported over 70% of their study subjects had less than a tertiary education, which was translated to low socio-economic status and a related poor knowledge of ill relatives' disorders and treatment.

The study show poor knowledge about type of mental illness of ill relatives. The finding is similar to a study [14] in Western Maharashtra, India, and reported that most of the participants had no prior knowledge about the disorders of their relatives. Another study in North West of England [18] shows inadequate information and failure of professionals to recognize the therapeutic benefits of caregivers' involvement in the clients' treatment program. Another study [19] argues that family caregivers teaching about illness of relatives

**Table 1:** Demographic Data of participants

Variable	Category	n=50	%
Gender	Female	31	62
	Male	19	38
Age (years)	18-33	20	40
	34-49	30	60
Married	Married	27	54
	Single	8	16
	Divorce	8	16
	Widow/Widower	7	14
Religion	Christian	41	82
	Others	9	18
Occupation	Public Servants	22	44
	Self Employed	17	34
	Farmers	6	12
	Students	5	10
	Education	Primary	33
	Secondary	11	22
	Tertiary	6	12
Relationship	Parent	14	28
	Wife	12	24
	Sibling	11	22
	Child	9	18
	Husband	4	8

**Table 2:** Family caregivers' knowledge about mental illness of ill relatives (n=50)

S/no.	Variable	Yes n %	No n %
1	Do you know the type of mental illness of your relative?	12 -24	38 -76
2	Do you know the correct name of your relative illness	8 -16	42 -84
3	Can you recognize the signs of relapse?	15 -30	35 -70
4	Will your ill relative get better with treatment?	43 -86	7 -14
5	Are you satisfied with care from the professionals?	33 -66	17 -34

**Table 3:** Family caregivers' knowledge about ill relatives treatment (n=50)

S/no.	Types of Information	Yes n %	No n %
1	Do you know the name of the medicine your relative is taking?	12 -24	38 -76
2	Without checking the prescription do you know the correct dosage/frequency of your relative medicine?	8 -16	42 -84
3	Can you recognize the side effects of the medicine?	23 -46	27 -54
4	Do you know how to handle the side effects of the medicine?	17 -34	33 -66
5	Do you know what the medicine (s) is supposed to do?	43 -86	7 -14
6	Does your relative take the medicine regularly as prescribed?	27 -54	23 -46
7	Apart from professional staff at the clinic, do you get medication information from other sources?	14 -28	36 -72

is one of the most empowering interventions mental health professionals especially nurses can implement. Thus, the need for caregivers knowledge and understanding of mental illness plays an important role in establishing good treatment outcomes.

The majority of study participants cannot recognize early signs of relapse. This confirms a previous study from this region that poor knowledge in managing symptoms of ill relatives contributed to the burden of family caregivers [3]. The study of Iseselo et al [20], reported that including family caregivers in planning and care has a strong influence on mental health outcomes. A study [14] in the United States, reported a decrease of about 50% in relapse, as family members participated in a psycho-education program. While another study [8], confirm that family caregiver's educational support programs enabled participants learn about the disorders and enhanced their coping strategies. Therefore, family caregivers need adequate information concerning treatment, discharge and how to manage symptoms of relapse or illness-crisis at home.

Majority of the participants reported that the illness of their relatives will improve with treatments. The finding is similar to a study in Ghana [17] that

reported family caregivers' anticipation of a cure was their main coping strategies. Another study in Nigeria [3] revealed that many family caregivers belief with treatment and support their relatives' illness will improve. To sustain positive patients' outcomes caregivers should have access to psycho-education and support from the treatment team.

The study shows that participants were satisfied with care rendered by mental health professionals. On the contrary, a study [21] in Malawi reported lack of effective cooperation and collaboration between caregivers and professionals. While another study [15], on barriers to family care in psychiatric settings, revealed that families identified fear of stigma, poor illness awareness, and lack of families' involvement in the treatment plan are causes of concerns for families in collaborating with health professionals. Furthermore, another study [10], reported that families experience problems in relating to health professionals and felt ignored and excluded from care. Thus family caregivers' involvement in care process plays a much larger role in the lives of their ill relatives.

The finding show poor information about treatment of ill relatives concerning the action, dosage

and side effects of medications. This confirms a study [18] that reported poor knowledge about side effects and non-adherence of prescribed medication as a major source of frustration for families and often the single biggest cause of relapse and re-admission of patients. Another study [22] revealed the importance of educating family caregivers about side effects and impact of non-adherence to medication to prevent relapse. Furthermore, evidence have shown that family caregiver's limited understanding about treatment impede care and a successful response to medication is an important point towards recovery [5,8].

Majority of the participants have poor knowledge dealing with the adverse effects of medications of ill relatives. Similarly, a study [19], reported that families are often excluded from medication management, and that caregivers do not discuss medication frequently with mental health professionals. Evidence has shown that caregivers understanding of medication management prepare them for the essential role of caring for their ill family members [23,24]. The understanding and management of medication side effects and non adherence will reduce the burden of care.

The study show majority of the participants' ill relatives take the prescribed medication regularly. The finding contrasts a study in North-eastern Nigeria [13] that reported an overall prevalence of 54.2% non-adherence. Another study [25] reported poor medication adherence among people with schizophrenia, and stressed the substantial impact of non-adherence on the disease progression, complication, functional outcomes and quality of life. Providing medication information and instructions that are appropriate to family caregiver's level of education may increase their understanding of the importance of adhering to treatment.

The finding shows caregivers only means of medication information are from professional staff at the clinic. Similarly, a study in Malaysia [2] on mental health

literacy among family caregivers of patients with schizophrenia, show caregivers rely only on nurses and doctors as their primary sources of information during consultation regarding mental health concerns of ill relatives. Therefore, education of caregivers about treatment is an important way of engaging families in the care.

### **Implication for Practice**

Mental illness places a huge burden not only on the individuals afflicted, but also the family members who live and interact with ill relatives in their daily life activities. Family caregivers experience stress due to inadequate knowledge and skills. Providing information and instructions that are appropriate to the family caregiver's level of education may increase their understanding of the importance of treatment. The degree to which family caregivers can understand basic health information can help them make wise decisions about care, Professionals need to collaborate and communicate effectively with caregivers to increase efficiency and positive treatment outcomes thus enhancing recovery.

### **Conclusion**

This study explored the knowledge of family caregivers about mental illness and treatment of their ill relatives. Mental health disorders strike without regard to age, gender, race, education, socio-economic and cultural boundaries. Poor knowledge and lack of access to information about illness of their relatives complicates the care giving process, and impedes their wellbeing. Mental health professionals should provide necessary information in a clear and understandable manner and explore the use of native languages when necessary. Education on medication adherence strategies should be tailored towards each family caregiver's understanding and level of education. Information about the disease, role of medication in controlling symptoms of the disorder, side effects of medication, types of treatments,

and support strategy should be provided. This type of information can relieve family caregivers' distress arising from uncertainties about their relatives' illness, and treatment.

### Limitation of the study

The study was limited to only family caregivers with at least a primary school education, and attending the out-patient psychiatric facility with their ill relatives for routine check-up. Future studies are suggested across multiple regions with caregivers of ill relatives attending to their follow-up care. The small sample size was due to low flow of patients and this may not provide a strong basis to make generalizations from the findings of this study. However, it provides a premise for a more comprehensive study in a larger facility.

### Authors Contribution

Author 1 was responsible for the study conception, literature review, questionnaire development, data collection, analysis and drafting of the manuscript, final revision and submission and Author 2 provided conception, literature review, questionnaire development, data collection, literature review, data analysis and editing.

### References

1. Jidda, M. S., Rabbebe, I. B., Omeiza, B., Wakhil, M. A., Ibrahim, A. W. et al. (2012). The Mental Health System in North-Eastern Nigeria: A WHO-AIMS Generated Assessment of the State of Mental Health in a Sub-Saharan African Region. *Nigerian Journal of Psychiatry*. 10(3).
2. Mohamad, M. S., Zabidah, P., Fauziah, I., & Sarnon, N. (2012). Mental Health Literacy among Family Caregivers of Schizophrenia Patients. *Asian Social Science*. 8(9): ISSN 1911-2017 E-ISSN 1911-202574.
3. Jack-Ide, I. O., Uys, L. R., & Middleton, L. E. (2013). Caregiving experiences of families of persons with serious mental health problems in the Niger Delta region of Nigeria. *International Journal of Mental Health Nursing*, 22, 170–179. doi:10.1111/j.1447-349.2012.00853.x
4. Chadda R, Singh T, Ganguly K. (2007). Caregiver burden and coping. A prospective study of relationship between burden and coping in caregivers of patients with schizophrenia and bipolar affective disorder. *Soc Psychiatry Psychiatr Epidemiol*. 42(11): 923–939.
5. Onwumere J, Kuipers E, Dunn G, Fowler D, Freeman D, Watson P, Garety P. (2008). Caregiving and illness beliefs in the course of psychotic illness. *La Revue, Canadienne de Psychiatrie*, 53, 7. 460-467.
6. Jack-Ide I.O & Uys L (2013). Barriers to mental health services utilization in the Niger Delta region of Nigeria: service users' perspectives. *Pan Afr Med J*.14: 159. doi: 10.11604/pamj.2013.14.159.1970
7. Robinson, W.D., Springer, P.R., Bischoff, R., Geske, J., Backer, E., Olson, M., et al. (2012) Rural Experiences with Mental Illness: Through the Eyes of Patients and Their Families. *Families, Systems, & Health*. 30, 308-321. <http://dx.doi.org/10.1037/a0030171>
8. Shankar, J., & Muthuswamy, S. S. (2007). Support needs of family caregivers of people who experience mental illness and the role of mental health service. *The Journal of Contemporary Social Services*. 302-310. DOI: 10.1606/1044-3894.3628.
9. Shinde, M., Desai, A., & Pawar, S. (2014). Knowledge, attitude and practice of caregivers of patients with schizophrenia in Western Maharashtra. *International Journal of Science and Research*; 3(5); 516-522.
10. Bland, R., & Foster, M. (2012). Families and Mental Illness: Contested Perspectives and Implications for Practice and Policy. *Australian Social Work*, 65,517-534.<http://dx.doi.org/10.1080/0312407X.2011.646281>

11. Sin, J., & Norman, I. (2013). Psychoeducational interventions for family members of people with schizophrenia: a mixed-method systematic review. *J Clin Psychiatry*. 74(12): e1145–e1162.
12. World Health Organization. (2013). Mental Health Action Plan 2013-2020. WHO, Geneva. [http://www.who.int/mental\\_health/publications/action\\_plan/en/](http://www.who.int/mental_health/publications/action_plan/en/)
13. Ibrahim, A. W., Pindar, S. K., Yerima, M. M., Rabbebe, I. B., Shehu, S. et al. (2015). Medication-related factors of non-adherence among patients with schizophrenia and bipolar disorder: Outcome of a cross-sectional survey in Maiduguri, North-eastern Nigeria. *Journal Neurosci. Behav. Health*. 7(5); 31-39. doi: 10.5897/JNBH2015.0128.
14. Lehman, A., Kreyenbuhl, R. W., Dickerson, F., Dixon, L. et al. (2004). The schizophrenia patient outcomes research team (PORT): Updated treatment recommendations 2003. *Schizophrenia Bulletin*. 30(2): 193-217.
15. Rugema, L., Krantz, G., Mogren, I., Ntaganira, J., & Persson, M. (2015). A constant struggle to receive mental health care: health care professionals' acquired experience of barriers to mental health care services in Rwanda. *BMC Psychiatry*. 15:314. doi 10.1186/s12888-015-0699-z.
16. Koolae, A. K., & Etemadi, A. (2010). The outcome of family interventions for the mothers of schizophrenia patients in Iran. *Int J Soc Psychiatry*. 56 (6):634–646.
17. Ae-Ngibise, K. A., Doku, V. C. K., Asante, K. P., & Owusu-Agyei, S. (2015). The experience of caregivers of people living with serious mental disorders: a study from rural Ghana. *Global Health Action*. 8: 26957 - <http://dx.doi.org/10.3402/gha.v8.26957>
18. Peters, S., Pontin, E., Lobban, F., & Morris, R. (2011). Involving relatives in relapse prevention for bipolar disorder: a multi-perspective qualitative study of value and barriers. *BMC Psychiatry*. 11:172 <http://www.biomedcentral.com/1471-244X/11/172>
19. Nuhu, F.T., Yusuf, A. J., Akinbiyi, A., Fawole, J. O., Babalola, O. J et al. (2010). The burden experienced by family caregivers of patients with epilepsy attending the government psychiatric hospital, Kaduna, Nigeria. *Pan African Medical Journal*, 5, 16.
20. Iseselo, M. K., Kajula, L., & Yahya-Malima, K. I. (2016). The psychosocial problems of families caring for relatives with mental illnesses and their coping strategies: a qualitative urban based study in Dares Salaam, Tanzania. *BMC Psychiatry*. 16:146. DOI 10.1186/s12888-016-0857-y
21. Chorwe-Sungani, G., Namelo, M., Chiona, V., & Nyirongo, D. (2015). The Views of Family Members about Nursing Care of Psychiatric Patients Admitted at a Mental Hospital in Malawi. *Open Journal of Nursing*, 5, 181-188. doi: 10.4236/ojn.2015.53022.
22. Giron, M., Nova-Fernandez, F., Mana-Alvarenga, S., Nolasco, A., Molina-Habas, A. et al. (2014). How does family intervention improve the outcome of people with schizophrenia? *Soc Psy-chiatry Psychiatr Epidemiol*. doi:10.1007/s00127-014-0942-9.
23. Lau, D.T., Kasper, J. D., Hauser, J. M., Berdes, C., Chang, C-H. et al. (2009). Family caregiver skills in medication management for hospice patients: a qualitative study to define a construct. *Journal of Gerontology: Social Sciences*, 64B(6): 799–807. doi:10.1093/geronb/gbp033.
24. Andersson, L. M. C., Schierenbeck, I., Strumpher, J., Krantz, G., Topper, K. et al. (2013). Help-seeking behaviour, barriers to care and experiences of care among persons with depression in Eastern Cape, South Africa. *Journal of Affective Disorders*. Available at <http://dx.doi.org/10.1016/j.jad.2013.06.022i>



25. American Pharmacists Association. (2013).Improving medication adherence in patients with severe mental illness. Pharmacy Today. 19(6); 69-80.