



STIGMA AND DISCRIMINATION AMONG INDIVIDUALS WITH MENTAL DISORDERS IN LAGOS, NIGERIA: A QUALITATIVE STUDY

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ABSTRACT

The increasing social stigma and discrimination against individuals with mental disorders have been reported to be of global public health concern especially in the developing countries. We investigated experiences of stigma and discrimination among individuals with mental disorders carried out by family members, friends, general public, co-workers and employers. Narrative interviews were conducted on 50 randomly selected patients from the outpatients' clinic of the department of psychiatry, Lagos State University Teaching Hospital, Ikeja, Lagos, Nigeria. Participants were asked open-ended questions on their personal experiences on negative stigmatising attitudes of family members, friends, general public, co-workers and employers. The majority of individuals living with mental illness emphatically claimed that they frequently experienced stigmatising attitude and discriminating behaviour from their family members, co-workers, employers and the general public. This study demonstrated that persons living with mental disorders experienced negative stigmatising behaviour by the close family members, friends, co-workers and general public. Clinicians and policy makers should further create awareness, advocacy and enlightenment programmes against social stigma and discrimination in the general population.

Keywords: Stigma, Discrimination, Mental Disorder, Qualitative Study, Lagos, Nigeria

INTRODUCTION

Individuals living with mental disorders represent a considerable proportion of the world's population most especially in the low and middle-income countries (Dako-Gyeke & Asumang, 2013; WHO, 2014). Studies have shown that one out of every four individuals will experience at any point in time different forms of mental illness (Dako-Gyeke & Asumang, 2013; WHO, 2014). The increasing social stigma and discrimination against individuals with mental health disorders have been reported to be a global public health issue (Thornicroft, Brohan, Rose, Sartorius & Leese, 2009; Thornicroft & Mehta, 2016). Several published empirical papers indicated that the mentally-ill, apart from experiencing disabilities from their mental disorders, also face problems associated with mental illness such as social stigma, exclusion and discrimination which make them to be stereotyped and maltreated (Thornicroft, Brohan, Rose, Sartorius & Leese, 2009; Faydi, Funk & Kleintjes, 2011; Thornicroft & Mehta, 2016). Published evidence indicated that an estimate of 76% to 99% of individuals with severe mental health disorders in low and middle-income countries may not receive professional mental health treatment and for those that may eventually receive professional treatments, they were likely to be managed by general practitioners, non-mental-health specialists, faith-based or traditional health practitioners (Gureje & Alem, 2000; Dinos, Stevens & Serfaty et al, 2004; Dako-Gyeke & Asumang, 2013). Scientific evidence also showed that the mentally-ill frequently suffer from human rights abuse, harmful and degrading treatment including lynching, inappropriate restrictions or incarceration, unhygienic or inhuman living conditions, homelessness, restricted rights to education or work, physical and sexual abuse, denial of civil rights to marry or political rights to vote, and frequent maltreatment in health facilities (Gureje & Alem, 2000; Dinos, Stevens & Serfaty et al, 2004; Dako-Gyeke & Asumang, 2013). One repeatedly reported reason that may explain why the mentally-ill find it difficult to access



professional mental health services was because of the associated social stigma and discrimination which were claimed to further increase their mental health burden and disabilities (Gureje & Alem, 2000; WHO, 2014; Jacob, Munro & Taylor et al., 2017).

In Nigeria, Gureje Lasebikan & Makanjuola, (2006) in one large scale community study reported that about 45% of Nigerians suffered from various types of mental health disorders and 23% of their respondents had seriously disabling mental illnesses such as anxiety disorders, unipolar and bipolar disorders, schizophrenia, epilepsy and substance use disorders. In the same vein, the prevalence of mental disorders, mental health social stigma and discrimination towards the mentally-ill were identified to be on the increase because of political apathy towards mental disorders, mental health legislation, limited mental health personnel, widespread ignorance and poor knowledge about mental illness and the mentally-ill (Gureje & Alem, 2000; Gureje & Lasebikan, 2006; Adewuya, Owoeye & Erinfolami, 2011). Previous empirical studies from Nigeria also showed that Nigerians had little knowledge and understanding of the aetiology of mental disorders which may also explain the perception that mentally-ill people were dangerous, hostile, violent and unpredictable (Gureje & Alem, 2000; Gureje & Lasebikan, 2006; Adewuya, Owoeye & Erinfolami, 2011).

Several reports have shown that appropriate and adequate development of mental health of the citizens of societies are also necessary for the improvement of societies because adequate mental health of citizens in any society will further create social stability which is a key determinant of societal well-being and quality of life (Coker, Olugbile & Eaton et al, 2011; WHO, 2014; Oshodi, Abdulmalik & Ola et al, 2014). The literature search showed few quantitative published studies on internalised and self-stigma from Nigeria (Gureje & Lasebikan, 2006; Adewuya, Owoeye & Erinfolami, 2011; Oshodi, Abdulmalik & Ola et al, 2014) but few studies had been carried out on the feelings and personal experiences of stigma and discrimination of individuals with mental illness. Both manual and electronic literature explorations did not reveal any qualitative research from Nigeria. The objectives of this study on nuclear and extended families, general public and workplace were used based on the design by Alexander and Link (2001). They reported that the relationship between persons with mental disorders and their family members is usually more personal than their relationship with friends, neighbours and co-workers. Similarly, they also noted that the interface between the mentally-ill and the general public their co-workers were different because public contact is not sought out, but work contact has to be chosen. To this end, this qualitative study was designed to determine:

1. How individuals with mental disorders are stigmatised and discriminated against by their nuclear and extended families
2. How persons with mental disorders are stigmatised and discriminated against by the general public which include friends and neighbours
3. How individuals living with mental disorders are stigmatised and discriminated against by their co-workers and employers.

METHODOLOGY

Study Design and Setting

This study was designed as a qualitative survey. The study took place at the department of psychiatry, Lagos State University Teaching Hospital, Ikeja, Lagos, Nigeria. Lagos State was the former administrative capital of Nigeria. It has an estimated population of 20 million people (World Population Review, 2017). The State has 20 Local Government Areas. Lagos State also has 57 flagship primary care centres with a total of 57 doctors and 625 nurses. The state can also boast of 24 general hospitals, with a total of 1005 doctors and 2088 nurses (Lagos State Ministry of Health, 2017). It has one tertiary teaching hospital with 327 doctors and 690 nurses in its employment. The tertiary institution is the Lagos State University Teaching Hospital, Ikeja, Lagos and it is located at Ikeja, the capital city of Lagos State. The hospital has 20 wards and also runs 25 outpatients' clinics. It runs in and outpatient services with 24-hour medical and surgical emergency services. It also offers undergraduate training for



medical students and postgraduate training for resident doctors. The hospital provides primary, secondary and tertiary healthcare services to the citizens of Lagos State due to its open door, walk-in government policy. There are no conditions for appointments or referrals to the general outpatients' department or the medical or surgical emergency departments of the hospital. The department of psychiatry runs an outpatients' clinic twice weekly. It also runs a clinic once a week for newly-referred patients. The department attends to about 60 to 80 patients per clinic day. The department has four consultant psychiatrists and 8 resident doctors.

Participants

This study employed a random sampling method to recruit 50 participants. The phenomenology approach was used for this study because it allowed respondents to disclose and also share personal experiences about their illness and how the respondents manage their day-to-day personal experiences. The number of respondents needed for a qualitative study became clear when new themes or explanations stopped emerging from the data that were being collected. For this qualitative study, the sample size of 50 was decided when no new information emerged from data being collected.

Measures

The open-ended questions that bothered on nuclear and extended family members were asked. These questions were: a) do your immediate family members talk to you in a bad ways regarding your illness? b) how did you react to their negative attitude? c) are you prevented from carrying out any duties at home because of your illness? The questions that bothered on public social stigma were: a) do your friends talk to you negatively about your illness? b) do people avoid you or react to you differently on the streets? c) in the hospital, how do people, hospital workers and other patients react to you? While the questions that bothered on co-workers and employers were: a) do your co-workers treat you differently because of your illness? b) have you been dismissed or suspended from your place of work due to your illness? c) would you tell new employers that you have suffered from mental illness before? d) has the illness affected your employability in any organisation in any way?

Data collection procedures

The collection of data was carried out through in-depth interviews with the respondents using unstructured open-ended questions and a voice recorder. Permission to use the voice recorder was sought from respondents. The open-ended interviews allowed respondents to talk freely about their illness in details. The open-ended interviews asked about experiences of stigma and discrimination in different life areas and it allowed the respondents to further clarify what needed to be understood by the researchers.

Inclusion criteria

Adult patients from the age of 18 years were already on neuroleptic medications for a minimal period of one year and who appeared to be stable and functioning well in community.

Exclusion criteria

Patients who were acutely disturbed and those that have not experienced mental illness for more than one year were excluded from the study.

Informed consent

Permission to carry out the study was sought from the Research and Ethics Committee of the Lagos State University Teaching Hospital, Ikeja, Lagos, Nigeria. Written consent was also obtained from every respondent before the interviews were carried out. The respondents were also assured about the confidentiality of the research.

**Statistical analysis**

Fifty interviews (one per participant) were conducted and audio-recorded. The recorded interviews were played back and listened to many times to accurately capture the necessary information from the respondent. The transcribed data were analysed to determine emerged significant themes. The dominant and very expressive quotations were extracted and qualitatively analysed to develop a typology of stigma and discrimination experiences.

RESULTS

The findings on sociodemographic characteristics showed that there were more females 28 (54%) than males 22 (43.1%), their ages ranged between 18 years and 64 years (Mean age 38.9 years; SD = 11.01), their educational status showed that 3 (5.9%) had no formal education, 12 (23.5%) had primary school education acquired, 16 (31.4%) had acquired secondary school education while 19 (37.3) had acquired tertiary education. With regards to marital status, about half 25 (50%) of the respondents were single, 18 (35.3%) were married and 7 (14.5%) were either divorced or separated from their spouses. Majority, 35 (68.6%) of the respondents, were Christians while the rest 15 (29.4%) were Muslims. More than half of the respondents, 27 (52.9%) were unemployed, 17 (33.3%) were gainfully employed and 6 (11.8%) were students. With regards to diagnoses, this study showed that 39.2%, 35.3%, 15.7% and 4% of the respondents were diagnosed with bipolar affective disorder, schizophrenia, depression and epilepsy respectively. The responses of the respondents from the qualitative interviews revealed recurring themes such as maltreatment, seclusion, social distancing, verbal abuse, and inability to be employed.

**Table 1 Sociodemographic characteristics of the participants**

Variable	n (50)	Percentage (%)	Mean, Median, Range, SD
Age Group			Mean = 38.9
20 - 20 Years	26	52	Median = 36.5
41- 60 Years	20	40	Range = 20-64
61 - 80 Years	4	8	SD = 1.91
Sex			
Male	22	44	
Female	28	56	
Education			
None	3	6	
Primary school completed	12	24	
Secondary School completed	16	32	
Higher Institution	19	38	
Marital Status			
Single	25	50	
Married	18	36	
Divorced/Separated	7	15	
Religion			
Christians	35	70	
Muslims	15	30	
Employment			
Unemployed	27	54	
Employed	17	34	
Students	6	12	
Diagnoses			
Schizophrenia	18	36	
Bipolar affective disorder	20	40	
Depression	8	15.7	
Epilepsy	4	7.8	



Our findings with regards to the families of the participant, these were the recurring themes during the in-depth interviews:

1. *"....My father and mother have neglected me and do not really care for me since I lost my job, they treat me anyhow and even abuse me with the illness..."*
3. *"...My husband thinks that I am unpredictable also believes that I could be violent because of that he moved out of the house and left me with four children..."*
4. *"....I will never forgive my father since the day he tied my hands and legs with rope because he claimed that I could be violent and not obey his instructions..."*
5. *"....My husband flares up frequently and anytime we argue, he calls me lunatic."*
6. *"... My uncle who I live with doesn't allow me to play with his children. He put me in a room in the boys' quarters and also doesn't allow me to touch their things anymore...."*
7. *"...My siblings sometimes call me mad man anytime I am arguing with them. They frequently say that - your illness has come back..."*
8. *"...My husband left me to marry another woman. He doesn't care for me or my upkeep anymore..."*

The revelation on the perceived experiences of the respondents on stigmatisation and discrimination by the general public which include friends and neighbours revealed these comments:

1. *".....My friends don't come to our house anymore and I also do not go to their houses because they are always making fun of me....."*
2. *"... In my church, one of our pastors asked for my ATM card and withdrew all the money in my account because I was confused and didn't know what I was doing while I was in their church...."*
3. *"....My boyfriend who had been quite supportive did not visit me during my last admission in the psychiatric ward, he kept on saying he was busy anytime the social workers called him. I haven't seen him till today....."*
4. *"... My parents stopped me from going back to school because my class mates were always abusing me and making fun of me..."*
5. *"... My friends gave me all sorts of nicknames such as wako jaco, aro-mental, mentallo, that is why I don't hang out with them anymore ..."*
6. *"...I used to belong to many social clubs, apart from not having enough money to go to such clubs anymore, my friends from my clubs don't call me or visit or invite me to their social functions anymore. ..."*

The experiences of persons living with mental illness were investigated with regards to their observation about social stigma and discrimination with their employers and colleagues at work. These were the comments of the respondents:

1. *"... Before I was diagnosed with mental illness, I was a secondary school teacher but because of my illness I was redeployed to the administrative room just to sit on one table doing nothing. ..."*
2. *".....I work in one hospital as an administrative officer, when I became ill mentally, my colleagues were always accusing me as being troublesome. The management of the hospital redeployed me to the psychiatric department as clerk. I am there till today...."*
3. *"....On discharge from the psychiatric hospital, my work colleagues got to know that I was on admission at the psychiatric hospital, their attitude towards me changed and I am always by myself at work, I do not interact with anybody anymore...."*
4. *".....I worked as a medical doctor in a private hospital, when I became sick, I was admitted at a psychiatric facility, on discharge from the hospital, my medical director terminated my employment. He gave a reason that he doesn't want a psychiatric doctor to attend to his patients. I am still looking for a new job now ..."*
5. *".....I stopped going to work because, I could not cope with the pressure of work due to my psychiatric drugs that often slow me down. I find it difficult to wake up early in the mornings. I was always getting to work late. Initially, my supervisor was tolerant,*



however, after about six months, he started complaining about my performance. The complaints were too much, I had to stop work. . . .”

DISCUSSION

The objectives of this study were to determine the social stigma and discrimination experienced by individuals living with mental illness with regards to their families, friends, general public, co-workers and employers of labour. With regards to diagnoses of the participants, this study showed that 39.2%, 35.3%, 15.7% and 4% of the respondents were diagnosed with bipolar affective disorder, schizophrenia, depression and epilepsy respectively. Therefore, it was expected that their experiences about their illness will differ because of the differences in their diagnoses. Published studies showed that the experiences of stigma and discrimination also vary with diagnosis. Persons with schizophrenia may not experience same stigmatising and discriminatory behaviour as those with epilepsy or anxiety disorders (Gureje & Lasebikan, 2006; Thornicroft, 2009; Rose et al, 2011; Faydi, Funk & Kleintjes, 2011; Whitley & Campbell, 2014; Jacob et al, 2017).

Concerning our findings on the stigma and discrimination experienced by individuals living with mental illness with regards to their families, friends, general public, co-workers and employers of labour, the results showed that majority of the participants experienced stigmatising attitude and discrimination from family members, colleagues at work, employers and the general public. Regarding the experiences on attitude of close family members, our findings showed that some family members had negative stigmatising attitude towards their own sick family member with mental illness. These findings were in agreement with other findings from other studies from other countries (Dinos et al, 2004; Stier & Hinshaw 2007; Barke, Nyarko & Klecha, 2011; Dako-Gyeke & Asumang, 2013; Hamilton, Lewis-Holmes, & Pinfold et al, 2014). These worrisome results could probably be due to lack of the limited knowledge about mental illness and aetiologies of mental illness by family members of the mentally-ill. This limited knowledge about mental disorders by family members of the mentally-ill may also be reason for perpetuating stigmatisation and discrimination within the family of the mentally-ill (Dinos et al, 2004; Stier & Hinshaw 2007; Barke, Nyarko & Klecha, 2011; Dako-Gyeke & Asumang, 2013; Hamilton, Lewis-Holmes, & Pinfold et al, 2014).

Other identified reasons for continuing stigma and discrimination within the family of the mentally-ill include over-pampering of the mentally-ill, high expressed emotions, and the general fear of the mentally-ill not being in control of his behaviours (Stier & Hinshaw, 2007; Lakeman, McGowan & MacGabhann et al, 2012; Ye, Chen & Paul et al, 2016). Published evidence showed that those with severe or chronic mental illness may eventually be isolated in secluded areas of the family house or just locked up in one room in the family house (Dinos et al, 2004; Stier & Hinshaw 2007; Barke, Nyarko & Klecha, 2011; Dako-Gyeke & Asumang, 2013; Hamilton, Lewis-Holmes, & Pinfold et al, 2014). Close family members also believed that their family members with mental illness could be unpredictable, verbally and physically hostile and capable of being employed (Dinos et al, 2004; Stier & Hinshaw 2007; Barke, Nyarko & Klecha, 2011; Dako-Gyeke & Asumang, 2013; Hamilton, Lewis-Holmes, & Pinfold et al, 2014). The implication of this is that the family which is believed to be the social unit of protection of family members from external societal aggression may not be performing that role because, social stigma and discrimination may eventually be occurring frequently in the families of persons with mental illness which can possibly precipitate relapses, reduced self-esteem and social withdrawal (El-Badri & Mellsop, 2007; Loganathan & Murthy, 2008; Dako-Gyeke & Asumang, 2013; Fernando et al, 2017).

With regards to the negative stigmatising attitude and discrimination by friends, neighbours and the general public, our findings showed that friends who were hitherto close to persons with mental illness withdrew or reduce their closeness once they discovered that their friend had suffered from mental illness. The respondents claimed that they were most times ridiculed by friends and the general public at large. In this light, scientific studies have severally indicated that the general public had limited knowledge about issues of mental health especially regarding the aetiologies and manifestations about mental illness (Alexander &



Link, 2001; Stier & Hinshaw, 2007; Thornicroft, Brohan & Rose, 2009; Barke et al, 2011; Al-Naggar, 2013; Hamilton, 2014; Oshodi et al, 2014; Fernando et al, 2017). Against this background, if the general public has limited knowledge about mental health and mental disorders, it could lead to misconceptions about the illness which could again bring about unceasing negative perception, social stigma, discrimination, prejudice and maltreatment of persons with mental illness. This may also explain why people living with mental illness were regularly isolated from the general public thereby preventing them from the opportunities that may enhance their quality life such as education, housing and marriage (Stier & Hinshaw, 2007; El-Badri & Mellsop, 2007; Thornicroft, Brohan & Rose, 2009; Barke et al, 2011; Hamilton et al, 2014; Klarić & Lovrić, 2017).

The respondents also claimed that they were given derogatory labels such as lunatics, mad, possessed, cursed, or might have even offended the gods. The consequences of these stigmatisation and negative attitude of Nigerians towards the mentally-ill may further prevent them from reaching out for proper psychiatric professional care and possible integration back to the community (WHO, 2006; Coker et al, 2011; Oshodi et al, 2014, Adewuya et al, 2011).

Another possible reason why negative beliefs were perpetuated by the general public could be due to the location of the stand-alone specialist psychiatric hospitals in the capital cities of Nigeria found to be far away from the reach of many Nigerians living in the rural areas (WHO, 2006; Gureje & Lasebikan, 2006; Coker et al, 2011; Oshodi et al, 2014). The distant location of the psychiatric specialists hospitals could be the reason why family members of the mentally-ill often patronise the herbal medical and faith-based practitioners found within their neighborhoods (WHO, 2006; Gureje & Lasebikan, 2006; Coker et al, 2011; Oshodi et al, 2014). The traditional and faith-based mental health practitioners were also observed to augment the faulty beliefs of the supernatural causes of mental illness, thereby fortifying their beliefs in the supernatural aetiologies of mental illness (WHO, 2006; Gureje & Lasebikan, 2006; Coker et al, 2011; Oshodi et al, 2014).

Concerning the employment of the respondents, our findings showed that a majority of the respondents were unemployed. Only 33.3% were gainfully employed. Many claimed that they lost their employment due to the nature of their illness, because they could not function optimally due to the side effects of the neuroleptic medications. Previous studies also showed that work colleagues of the mentally-ill persons were not comfortable working with them due to the perception that they could be unpredictable and dangerous thereby socially distancing themselves from the mentally-ill persons. Our respondents also claimed that they were always ridiculed, shunned, mocked and abused at their various places of work. Empirical evidence indicated that most employers of labour were less likely to employ individuals with mental illness. Even those employed among the respondents claimed that they were often labeled and discriminated against at their work places (Brohan & Thornicroft, 2010; Adewuya et al, 2011; Oshodi et al, 2014; Dako-Gyeke & Asumang, 2013). The observed behaviour of workers towards the mentally-ill could probably explain why employed mentally-ill individuals often conceal their illness from prospective employers and co-workers (Brohan & Thornicroft, 2010; Adewuya et al, 2011; Oshodi et al, 2014; Dako-Gyeke & Asumang, 2013; Klarić & Lovrić, (2017). The limited knowledge about mental illness and mental disorders by the general public at large which also include family members and employers possibly explain the rising levels of social stigma and discrimination towards the mentally-ill. This also explains why employers of labour may refuse to employ those living with mental illness or might even terminate their appointments because they believe that the mentally-ill may become unproductive (Brohan & Thornicroft, 2010; Barke et al, 2011; Adewuya et al, 2011; Oshodi et al, 2014; Dako-Gyeke & Asumang, 2013; Klarić & Lovrić, (2017).

The negative findings of this study on stigma and discrimination about family members, co-workers and the general public about mental illness and the mentally-ill could be very bothersome. Therefore there is an urgent need for regular and continuous awareness programmes mental health and mental illness by mental health specialists and policy makers. The consequences of limited knowledge and awareness about mental health and mental illness could continue to perpetuate the negative perception, stigma and discrimination of the



mentally-ill not only in nuclear and extended families but also in the Nigerian general population. This negative attitude may further prevent Nigerians living with mental illness to receive adequate professional mental health care.

This study too has its limitations. The sample was relatively small and the participants may not want to totally share embarrassing experiences. Nonetheless, the study should be generalised with caution. However, the participants provided their subjective significant experiences of stigma and discrimination which contributed to the body of knowledge on qualitative investigations of individuals with mental illness.

CONCLUSION

The shared subjective personal experiences by the participants assisted in illuminating negative stigmatising behaviour of family members, co-workers and the general public towards the mentally-ill. It is therefore important that Nigerian mental health practitioners and policy makers should urgently address the stigma and discrimination associated with mental illness in order to encourage persons living with mental health to live fulfilling quality lives. Mental health experts should continue to create awareness, advocacy and enlightenment programmes against social stigma and discrimination against the mentally-ill especially in developing countries such as Nigeria.



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