

**A study of the role of consumer and family groups and their
potential contribution to mental health policy and services in
Nigeria.**

**Submitted by
Olusola Toluwanimi EPHRAIM-OLUWANUGA**

Master's dissertation in International Mental Health

Supervisor: Professor Jose Miguel Caldas de Almeida

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DECLARATION

I hereby declare that that this work is original unless otherwise acknowledged. It has not been submitted to any other College or Institution for a degree or diploma, neither has it been published elsewhere

Dr Olusola Toluwanimi Ephraim-Oluwanuga

CERTIFICATION

The study reported in this dissertation was conducted by Dr Olusola T. Ephraim-Oluwanuga

Under the supervision of Professor Jose Miguel Caldas de Almeida

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Abstract

Nigeria, a Lower Middle Income Economy with an estimated population of over 182 million, has a large mental health treatment gap. In addition, people with mental health conditions suffer from stigmatization and severe human rights abuses.

Nigeria has made minimal progress towards improving access to mental healthcare services. Probably, contributing to this situation is the lack of stakeholder advocacy for mental health. Hitherto, family and consumer groups have not been involved as stakeholders in mental health. This study examined the role of consumer and family groups and their potential contribution to mental health policy and services in Nigeria.

The study was conducted through a survey design. First, questionnaires were emailed to Psychiatrists nationwide. A functioning group of users and family members was identified in Ibadan, South-Western Nigeria. Then an in-depth questionnaire was administered to the facilitator of the group to obtain the details of the administrative running of the group. Finally, questionnaires were administered to members of the group.

A nationwide email survey of Psychiatrists was able to identify two consumer groups, one of which was studied, as the other was logistically inaccessible. Practitioners showed a good understanding of the roles and potentials of consumer groups.

This study has profiled The Family Support Group, a consumer group operating in Ibadan, Nigeria. The group was found to be relatively small but vibrant, one whose members are enthusiastic. However, members seemed more focused on the shared emotional support and obtaining of health information, thus preventing relapse, than on engagement with government or public advocacy.

Training and support in specific areas are recommended, stimulating the group to broaden its scope of activity. Further studies will be required to determine the potential for growth and replication of such groups and the impact of this development on mental health policy and services.

Key words: Mental Health, Consumer, Stakeholder, Advocacy, Nigeria

Resumo

Introdução: A Nigéria, uma economia de rendimento médio baixo com uma população estimada de mais de 182 milhões, tem uma grande lacuna no tratamento dos problemas de saúde mental. Além disso, as pessoas com problemas de saúde mental sofrem de estigmatização e graves violações dos direitos humanos.

A Nigéria fez progressos mínimos no sentido de melhorar o acesso aos serviços de saúde mental.

Provavelmente, a falta de advocacia das partes interessadas no que respeita à saúde mental contribui para esta situação. Até agora, famílias e grupos de consumidores não foram envolvidos como partes interessadas na saúde mental.

Este estudo examinou o papel dos grupos de consumidores e familiares e sua contribuição potencial para as políticas e os serviços de saúde mental na Nigéria.

Método: O estudo foi conduzido através de um inquérito. Primeiro, foram enviados questionários por e-mail para psiquiatras em todo o país. Um grupo funcional de utilizadores e familiares foi identificado em Ibadan, no sudoeste da Nigéria. Em seguida, um questionário detalhado foi administrado ao facilitador do grupo para obter os detalhes do funcionamento administrativo do grupo. Finalmente, foram administrados questionários aos membros do grupo.

Resultados: O inquérito nacional enviado por e-mail aos psiquiatras permitiu identificar dois grupos de consumidores, um dos quais foi estudado, uma vez que o outro era logisticamente inacessível. Os profissionais mostraram uma boa compreensão dos papéis e potencialidades dos grupos de consumidores.

Este estudo estabeleceu o perfil do The Family Support Group, um grupo de consumidores que opera em Ibadan, na Nigéria. O grupo é relativamente pequeno, mas vibrante, e os seus membros são entusiastas. No entanto, os membros pareciam mais focados no apoio emocional compartilhado e na obtenção de informações de saúde, prevenindo assim a recaída, do que no engajamento com o governo ou a defesa pública.

Conclusões: Como recomendações sugere-se que sejam proporcionados formação e apoio em áreas específicas, de forma a estimular o grupo a ampliar seu campo de atividade. Serão necessários mais estudos para determinar o potencial de crescimento e replicação desses grupos eo impacto desse desenvolvimento nas políticas e nos serviços de saúde mental.

Palavraschave: Saúde mental, Utilizadores, Parceiros, Advocacia, Nigeria

Resumen

Introducción: Nigeria, una economía de ingresos medios bajos con una población estimada de más de 182 millones, tiene una gran brecha de tratamiento en salud mental. Además, las personas con problemas de salud mental sufren estigmatización y graves abusos contra los derechos humanos.

Nigeria ha hecho progresos mínimos para mejorar el acceso a los servicios de salud mental. Probablemente, la falta de apoyo de los grupos de interés para la salud mental contribuye para esta situación. Hasta ahora, los grupos de familiares y de consumidores no han participado como actores en la salud mental. Este estudio examinó el papel de los grupos de consumidores y familiares y su posible contribución a las políticas y los servicios de salud mental en Nigeria.

Métodos: El estudio se realizó a través de un diseño de encuesta. Primero, los cuestionarios fueron enviados por correo electrónico a los psiquiatras de todo el país. Un grupo funcional de consumidores y miembros de la familia fue identificado en Ibadan, Sudoeste de Nigeria. A continuación, se administró un cuestionario en profundidad al facilitador del grupo para obtener los detalles del funcionamiento administrativo del grupo. Finalmente, se administraron cuestionarios a los miembros del grupo.

Resultados: Una encuesta nacional de los Psiquiatras hecha por correo electrónico fue capaz de identificar dos grupos de consumidores, uno de los cuales fue estudiado, ya que el otro era logísticamente inaccesible. Los profesionales mostraron una buena comprensión de los roles y potenciales de los grupos de consumidores.

Este estudio ha perfilado The Family Support Group, un grupo de consumidores que opera en Ibadan, Nigeria. El grupo es relativamente pequeño pero vibrante, uno cuyos miembros son entusiastas. Sin embargo, los miembros parecían más centrados en el apoyo emocional compartido y la obtención de información sobre la salud mental, evitando así la recaída, que en el compromiso con el gobierno o la defensa pública.

Conclusión: Se recomienda la capacitación y el apoyo en áreas específicas, estimulando al grupo a ampliar su campo de actividad. Se necesitarán estudios adicionales para determinar el potencial de crecimiento y replicación de estos grupos y el impacto de este desarrollo en las políticas y servicios de salud mental.

Palabras clave: Salud mental, Usuarios, Partes interesadas, Advocacia, Nigeria

TABLE OF CONTENTS

Cover Page.....	i
Declaration.....	ii
Certification.....	iii
Acknowledgements.....	iv
Abstract in English.....	v
Abstract in Portuguese.....	vi
Abstract in Spanish.....	vii
Table of contents.....	viii-x
Abbreviations.....	xi
List of Figures.....	xii
List of Tables.....	xii
List of Boxes.....	xii

CHAPTER ONE

INTRODUCTION.....	1-3
1.0 Introduction.....	1-2
1.1 Research question.....	3
1.2 Objectives.....	3

CHAPTER TWO

LITERATURE REVIEW	4-13
2.0 Introduction.....	4
2.1 The burden of mental illness.....	4-5
2.2 The Mental Health Gap Action Programme (mhGAP).....	5
2.3 The State of Mental Health services in Nigeria and the treatment gap.....	5-8
2.4 Nigerian Mental Health Policy.....	8-9
2.5 Nigerian Mental Health legislation.....	9
2.6 Stigma and discrimination in Nigeria	10

2.7 The role of Consumer and Family Support Groups Worldwide.....	10-13
2.7.1 National Alliance on Mental Illness.....	11
2.7.2 World Fellowship for Schizophrenia and Allied Disorders.....	11-12
2.7.3 European Federation of Families of People with Mental Illness (EUFAMI).....	12
2.7.4 World Federation for Mental health	12-13
CHAPTER THREE	
METHODOLOGY.....	14-15
3.1 Study design.....	14
3.2 Study setting.....	14
3.3 Study Instruments.....	14-15
3.4 Ethical considerations.....	15
3.5 Data collection.....	15
3.6 Data Analysis.....	15
CHAPTER FOUR	
RESULTS.....	15-30
4.0 Introduction.....	16
4.1 Survey of Psychiatric hospitals and facilities in Nigeria.....	16-20
4.2 A description of the Ibadan Consumer/Family Support Group.....	20-23
4.2.1 About the Group and the Services it provides.....	21
4.2.2 Consumer Information and Education provided by the Group.....	22
4.2.3 Consumer representation and Advocacy provided by the Group.....	23
4.3 A study of The Ibadan Family Support Group.	23-30
4.3.1 Demographic data of a sample of members of the Ibadan group.....	23-24
4.3.2 Membership drive, regularity of attendance & overall perception of the group.....	24-25
4.3.3 Reasons for attending meetings of the group.....	25-26
4.3.4 Perceived benefits of belonging to the group.....	26-27
4.3.5 Regrets about belonging to the group.....	27-28

4.3.6	Perception about location of support group meetings.....	28-29
4.3.7	Activities of the group actual and desired.....	29-30
CHAPTER 5		
	Discussion	31-39
5.0	Introduction.....	31
5.1	Thesis findings in context.....	31-38
5.1.1	Survey of Psychiatric and facilities in Nigeria.....	31-32
5.1.2	The Family Support Group (FSG) in the light of the objectives of this study.....	32-38
5.1.2.1	Current state of the Group and its evolvement.....	32-35
5.1.2.3	Members' role and potential in mental health policy formation & legislation..	35-36
5.1.2.4	Members' perception of their role.....	36-37
5.1.2.5	The Group's achievements so far.....	37
5.1.2.6	The Group's challenges.....	37
5.1.2.7	Assessment of The Group's needs.....	37-38
5.2	Strengths and Limitations of the study.....	38
5.3	Implications for theory, clinical practice, policy and research.....	38-39
CHAPTER SIX		
	Conclusions and recommendations.....	40-42
	Conclusions.....	40-41
	Recommendations.....	41-42
	References.....	43-45
APPENDICES.....		
	Appendix I: Questionnaire for Staff of Departments of Psychiatry/Neuropsychiatric Hospitals in Nigeria.....	46-47
	Appendix II: The Modified Stock Take and Needs Assessment of Consumer Organisation and Groups Questionnaire.....	48-60
	Appendix III: Questionnaire for Service Users of Departments of Psychiatry/Neuropsychiatric Hospitals in Nigeria.....	61-63
	Appendix IV: Questionnaire for Service Users of Departments of Psychiatry/Neuropsychiatric Hospitals in Nigeria (Yoruba version).....	64-67

ABBREVIATIONS

CAMIMH	Canadian Alliance on Mental Illness and Mental Health
EU	European Union
EUFAMI	European Federation of Families of People with Mental Illness
FSG	Family Support Group
HIV/AIDS	Human Immunodeficiency Virus Infection and Acquired Immune Deficiency Syndrome
LAMICS	Low and Middle Countries
MIAW	Mental Illness Awareness Week
MNS	Mental, Neurological or Substance use
NAMI	National Alliance on Mental Illness
NGO	Non-governmental Organization
PPP	Purchasing Power Parity
UN	United Nations
WFMH	World Federation for Mental Health
WFSAD	World Fellowship for Schizophrenia and Allied Disorders
WHO	World Health Organisation

LIST OF FIGURES

Figure 1- Geopolitical Distribution of Hospitals surveyed all over Nigeria

Figure 2- Mental health consumer groups functioning under the auspices of hospitals surveyed

Figure 3- Means by which respondents learnt about Family Support Group

Figure 4- Respondents perception about benefits of belonging to Support Group

Figure 5- Respondents views about having mental health consumer groups in their community

Figure 6- Respondents preferred venue to attend group meetings

LIST OF TABLES

Table 1- Preliminary findings about functioning of consumer groups in Nigerian hospitals

Table 2- Practitioners' attitudes towards the establishment of consumer groups

Table 3- Demographic characteristics of Family Support Group respondents

Table 4- Family Support Group respondents' participation in The Group

Table 5- Reasons for attending Family Support Group meetings

Table 6- Benefits of participating in The Group

Table 7- Regrets about belonging to The group

Table 8- Areas of activity of The Family support group.

LIST OF BOXES

Box1- Nigeria: Health Statistics

Box 2- Desired activities for proposed consumer group (Practitioners)

Box 3- Four activities considered the most important for consumer groups (Practitioners)

Box 4- Other useful comments to further enrich the interview

Box 5- Regret about belonging to the group

Box 6- Activities considered to be most important by consumers

Box 7- Activities respondents would like to see the group engaged in which have not yet commenced

CHAPTER 1

INTRODUCTION

1.0 Introduction

This chapter provides an introduction to the subject matter of this thesis. It provides background information about the organization and the state of mental health care services in Nigeria. It also reviews the barriers to improvement created by the lack of engagement of stakeholders. An introduction to the aim of the thesis, the research questions as well as the objectives of the study is also given.

Nigeria with an estimated population of over 182 million people is Africa's most populous country and is classified as a Lower Middle Income Economy by the World Bank⁽¹⁾. Nigeria has a large mental health treatment gap⁽²⁾. Jacob et al⁽³⁾ in The Lancet Series reported that Nigeria has one of the poorest rates of mental health interventions for persons in need among 192 countries studied. In addition people with mental health conditions suffer from stigmatization and severe human rights abuses⁽⁴⁾⁽⁵⁾.

Since The World Health Organisation (WHO) declared that there is no health without mental health⁽⁶⁾ there has been a global drive to improve access to mental healthcare services and Nigeria has been a participant in this effort. However the progress made has been minimal, probably because whenever a service is provided, consumer feedback is an important part of quality control⁽⁷⁾. This consumer feedback is absent from the Nigerian Mental Health system because of the virtual non-existence of active consumer groups.

Worldwide, consumer organisations have developed and they have become very influential in affecting policy, in driving research and development of new drugs and treatment methods and in the provision and designing of various mental health services. Consumer groups also help to promote social integration of persons living with mental disorders, help to educate the public and combat stigma⁽⁸⁾. For this reason, it is desirable for health care providers, government and policy makers to engage with consumers if they are truly desirous of providing quality services, particularly in view of the limited resources available. Indeed in the 2001 World Health report, the WHO recommended the involvement of communities, families and consumers as part of the effort to strengthen the mental health system and enable provision of care⁽⁹⁾.

However, in Nigeria this important component is lacking. Indeed, Saraceno et al (2007), in the fifth of the seminal Lancet series addressed barriers to improvement of mental health services in low-income and middle-income countries (LAMICS), concluded that population-wide progress in accessing mental health care will depend substantially on paying more attention to politics, leadership, planning, advocacy and participation⁽¹⁰⁾. Advocacy and participation are roles best driven by consumer organisations in collaboration with mental health care professionals.

It is noteworthy that in Nigeria, most of the payment for mental health services is out of pocket. Consumers, who are often unemployed and their families, who are often poor, have to pay cash. The National Health Insurance coverage is less than 3% nationwide⁽¹¹⁾ and it does not pay for all the services that are related to mental health. This factor should in fact emphasise consumers as stakeholders, but that is not the case at present. Probably because they are not organised in groups, consumers have no formal recognition, neither are they considered for any role when services or policies are being planned or implemented. Yet the development and growth of consumer and family groups is a potential tool for the development of mental health services in Nigeria which may be easier to tackle than other problem areas such as manpower development, improved funding and bridging the treatment gap. Indeed, if properly marshaled, strong consumer and family groups could drive the growth of these other aspects.

Nigeria's National Council for Health adopted a new mental health policy in 2013. The policy has not yet been backed up by a plan and so it remains largely unimplemented to date. Nigeria is one of the few countries in the world with no modern mental health legislation. The country still operates under the Lunacy Act of 1958, inherited from the British Colonial Government⁽¹²⁾ in spite of two attempts to pass legislation in 2004 and 2013. The situation occurs against a background of grossly inadequate budgetary provision for mental health. Only 3% of the health budget goes to mental health and none of this is for mental health programmes. Rather the little funding goes into running eight Federal Neuro-psychiatric Hospitals⁽¹³⁾.

One key contributor to the suboptimal state of mental health services and policy implementation in Nigeria is probably a lack of stakeholder advocacy for mental health⁽¹⁰⁾. Internationally, family and consumer groups are regarded as stakeholders in mental health. However, in Nigeria there is no involvement of consumers and family in any recognised way. Although a few consumers and family were invited when the mental health policy was being drafted, they attended as individuals because there was not a single identified consumer and family support group identified.

Similarly, there was no involvement of consumer and family groups when attempts were made to pass new mental health legislation. Not surprisingly the attempts have failed so far, probably in part because the legislators did not see any significant public agitation or pressure seeking for the draft legislation to be passed.

In addition, vibrant family groups could play an important role in fighting stigma, discrimination and human rights abuses. This is another important reason for the investigation of the proposed thesis subject. Given the fact that there are at least an estimated 25 million people who would benefit from mental health services in Nigeria⁽¹⁴⁾, it could turn out to be a potent force for positive change to have a good proportion of these mental health consumers and their families as advocates for mental health.

1.1 Research questions

The above-mentioned observations led to the framing of the research question for this thesis: What is the role of consumer and family groups and what could be their potential contribution to mental health policy and services in Nigeria?

1.2. Objectives

The aim of this thesis is to study the role of consumer and family groups and their potential contribution to mental health policy and services in Nigeria.

This will be achieved by pursuing the following objectives: to develop a database of consumer and family groups in Nigeria and study such groups in terms of their:

- a.) Current state.
- b.) Evolvement.
- c.) Role in present mental health care services (actual and potential).
- d.) Role in mental health policy formation and legislation (actual and potential).
- e.) Achievements so far.
- f.) Challenges.
- g.) Perception of their role.
- h.) Assessment of their needs.

The implications for policy and practice of the findings will also be discussed, and relevant recommendations for policy and further research will set forth.

CHAPTER 2

LITERATURE REVIEW

2.0. Introduction

This chapter reviews the literature pertaining to the subject matter of the dissertation. It reviews this against background related material such as the burden of mental health in Low and Middle Countries (LAMICS), including Nigeria, the state of mental health in Nigeria, Nigerian Mental Health Policy and Nigerian Mental Health legislation, Stigma and discrimination in Nigeria, and the role of consumer and family support groups worldwide including some specific examples of well-established internationally recognised groups.

2.1. The burden of Mental Illness.

It is pertinent to begin this chapter with a review of the burden of mental illness. The reason is because whenever the burden of mental illness is mentioned by researchers and health planners alike, it is described in numbers and statistics, but to mental health consumers and their family members, burden is personally felt. It impacts their lives and choices in so many important ways every day of their lives. Therefore, the consumers would be expected to be the most desirous of having the burden of mental illness to be maximally reduced if not totally eliminated. This means that consumers may be expected to be a willing and active partner when mental health reform is considered, provided that such reform is viewed positively and provided the consumers are organized and have a platform to make their views heard.

The global burden of mental illness was first highlighted by The World Bank in its World Development Report 1993⁽¹⁵⁾. The Global burden of disease study showed that Mental and neurological disorders account for 14% of the global burden of disease and contribute 28% of the burden of disease attributed to non-communicable disease⁽¹⁶⁾.

WHO estimates that 450 million people suffer from these disorders, and that in the course of a lifetime, one in every four persons will be affected by a mental, neurological or substance use (MNS) disorder. In Nigeria, the lifetime prevalence rate of mental disorders ranges from 12.1% to 26.2% based on community surveys⁽¹⁴⁾. Projected at the same levels to today's population of 182 million, this would translate into between 22 and 47 million people who bear the burden of MNS disorders. When the families and caregivers of these people are added on, the figures are even more staggering.

The high burden of mental and neurological conditions that has been reported is disproportionately high on the most disadvantaged and poorly resourced regions of the world. About 70% of the global burden of mental disorders is borne by people who live in LAMICs, even though these countries possess only 10% of the global mental health resources⁽¹⁶⁾.

To further compound the dismal picture, LAMICs often have to deal with the dual problems of increasing levels of non-communicable diseases - such as mental disorders and diabetes, superimposed on the endemic problems of communicable disease such as malaria, HIV/AIDS and tuberculosis, thus depleting the resources available to deal with MNS disorders and further stressing the weak health systems of these countries⁽¹⁷⁾.

2.2. The Mental Health Gap Action Programme (mhGAP).

Concerned about reducing the global burden of mental ill health, the 55th World Health Assembly endorsed the Mental Health Global Action Program in 2002, thus placing mental health on the global public health agenda. But recognizing the gap between what was urgently needed and what was available to reduce the burden, WHO launched The Mental Health Gap Action Programme (mhGAP) in 2008. This was developed particularly for LAMICS, to scale up services for the treatment of mental, neurological and substance use (MNS) disorders in order to reduce their huge treatment gap⁽¹⁸⁾.

The WHO World Health Surveys revealed that there is a large treatment gap of about 80% in Nigeria. It also revealed that between 76 and 85.4% of people with mental illness in LAMICs did not receive any treatment in the preceding year⁽²⁾.

Nigeria was one of the countries identified for urgent intervention via the mhGAP and WHO partnered with the Federal Ministry of Health. A Mental Health Action Committee was inaugurated by the Federal Ministry of Health (FMOH) to oversee its smooth roll out. The committee chaired by a Professor of Psychiatry, who had participated in the World Mental Health Survey, had representatives from FMOH, Association of Psychiatrists in Nigeria, Psychologists, Social Worker, The Armed forces, Police and Prison services, National Human Rights Commission and Non-Governmental Organisations in the field of mental health, but consumers were not represented. There was no consumer group found at the time.

So far, the mhGAP guide has been contextualized for use in Nigeria, mhGAP has been rolled out in two pilot states (out of thirty-six in the country) and more recently, the mhGAP Humanitarian Intervention Guide (mhGAPhig) has been introduced and is in use in 3 states where there has been insurgency, with thousands of internally displaced persons currently living in camps.

All of these are positive steps, but since the essence of mhGAP is partnerships to improve investment in mental health, and such partnerships are meant to include partnerships with service users and their families, it is necessary to carry along consumers in order to better fulfil the original purpose for which the programme was initiated.

2.3. The State of Mental Health services in Nigeria and the treatment gap.

A basic assumption of this research endeavour is that having effective consumer groups would lead to improved mental health services. Therefore, in order to further appreciate

the potential role for mental health service user groups, it is necessary to briefly review the present state of mental health services in Nigeria.

Mental health services are a subset of the entire health system in Nigeria, which is itself in dire need of strengthening in many areas.

Below are some statistics that reveal the state of health services as well as other relevant socioeconomic indices in Nigeria are as follows:

- 1) Life expectancy at birth (years): **M (54), F (55)**
- 2) Infant mortality rate (probability of dying by age 1 per 1000 live births): **74.3**
- 3) Under-five mortality rate (probability of dying by age 5 per 1000 live births): **117.4**
- 4) Literacy rate among adults aged ≥ 15 years (%): **61**
- 5) Net primary school enrolment rate (%): **M (60), F (55)**
- 6) Gross national income per capita (PPP int. \$): **5,360**
- 7) Population living on $< \$1$ (PPP int. \$) a day (%): **62.0**
- 8) Cellular phone subscribers (per 100 population): **73**
- 9) Density of physicians per 10,000 population: **4.1**
- 10) Density of psychiatrists per 10,000 population: **<0.05**
- 11) Psychiatric beds (per million population): **1.5**
- 12) Per capita total expenditure on health at average exchange rate (US\$): **93(2012)**
- 13) Per capita government expenditure on health at average exchange rate (US\$): **31(2012)**
- 14) Out-of-pocket expenditure as % of private expenditure on health: **95.5 (2012)**
- 15) Total expenditure on health as % of gross domestic product: **3.4**
- 16) General government expenditure on health as % of total expenditure on health: **33.2**
- 17) Private expenditure on health as % of total expenditure on health: **66.8**
- 18) General government expenditure on health as % of total government expenditure: **18.0**
- 19) External resources for health as % of total expenditure on health: **5.5**
- 20) Percent of Population living in urban areas: **46**

Source: W.H.O 2015, World health statistics 2015⁽¹⁹⁾ Box 1. Nigeria: Health Statistics

These statistics show Nigeria to be often lagging behind countries with a lower per capita income, which would be an indication that the poor state of health services in Nigeria could in part be attributable to issues of poor governance. And this means that civil society, including consumer groups would have a role to play in working towards positive and sustainable reform.

Although worldwide, the mental health services tend to lag behind the general health services, the gap has been documented to be worse in LAMICS.

Scarce mental health funds are spent on long-term institutional care at mental hospitals and on new, patented, pharmaceuticals which, in general, are much less cost effective than community-based care and generic essential medicines⁽²⁰⁾⁽²¹⁾.

There have been two sets of journal series published in The Lancet that have addressed problems responsible for the poor state of mental health services in LAMICS and proffered solutions. According to The Lancet global mental health series,⁽²²⁾⁽²³⁾⁽²⁴⁾⁽²⁵⁾⁽¹⁰⁾⁽²⁶⁾ some of the main problems of mental health systems in LAMICs include:

1. Inadequate funding

2. Inadequate staff
3. Inadequate access
4. Stigma

In the 5th paper of the first Lancet series, Saraceno et al. identified 4 major barriers to the development of mental health services in LAMICS

1. *Absence of mental health from the public health priority agenda* (low prioritization). This has been considered as the greatest and most fundamental barrier to the development of mental health care services. The failure to portray mental health as vital to overall national development strategy and thus place it squarely within the national health priority has led to neglect of mental health, poor government funding and low donor interest.
2. *Poor organisation of services.* The centralization of mental health services within the tertiary health care system, in large institutions in big cities has been a great barrier to access. Such institutions, which usually command the bulk of the meager resources allocated to mental health, isolate the patients from family and community support. They also are associated with undignified life conditions, violations of human rights and perpetuation of stigma.
3. *Complexity of integrating mental health care effectively with primary care services.* This is related to barrier 2 above. The primary health care systems are overburdened and the staff do not receive the support and supervision they require to provide mental health services with the little training they have. There is also a poor referral system, worsened in Nigeria by the weakness and often total absence of mental health care at the secondary care level.
4. *Lack of effective public health leadership.* It is often assumed, and wrongly so, that Psychiatrists, who are leaders of the mental health care services, would have the skills to provide good management and effective advocacy to advance the cause of mental health. Unfortunately, this is not true because very little in the training of Psychiatrist prepares them for this role. Therefore, it is important that Psychiatrists obtain additional Public health training, and that public mental health should be included in the medical school and Postgraduate college curricula.

The above-mentioned barriers highlighted in The Lancet series even though are described with regards to LAMICS, are all relevant to the Nigerian context. In addition, there are certain problems specific to the mental health system in Nigeria such as:

1. The lack of modern mental health legislation and lack of the implementation of mental health policy. This is a major barrier in Nigeria. This problem which underpins a lot of issues and requires urgent attention will be discussed further below.

2. The problem of out of pocket payment. Again requires policy and legislative intervention. It is important to devise ways of ensuring free treatment for certain mental health conditions or classes of people with mental illness. This will require multi-sectoral collaboration and consumer groups would be valuable advocates.
3. The problem of corruption and seeking for position. Allocated funds may be misapplied, people may seek to occupy management positions for which they lack the skills or competence, etc. These are all problems that further weaken the mental health services. Again, policy, education, and consumer empowerment will be required to address these problems.
4. The problem of poor data and insufficient research in the area of health systems and services. There is insufficient research into health systems and policy and this means that there is insufficient hard evidence to present to policy makers when advocating for change.

All the above-mentioned areas are potential points of advocacy and positive action by mental health consumer groups as has been done in other countries⁽⁸⁾.

2.4. Nigerian Mental Health Policy

One of the key factors responsible for the poor state of mental health in Nigeria is the lack of implementation of a mental health policy. Nigeria's first Mental Health Policy was passed in 1991⁽²⁷⁾. It was a brief document which outlined broad policy directions and it was largely unimplemented. It had no mental health action plan to back the document or drive its implementation.

The 1991 policy was a commissioned document prepared by a few mental health experts. It was drawn up as a platform for the integration of mental health into primary health care in the spirit of the declaration of Alma Ata, calling for Health for all by the year 2000. It did not have the buy-in of the relevant stakeholders because there is no evidence that they were ever identified or consulted for that purpose.

In 2013, a new mental health policy was adopted by the National Council of health⁽²⁸⁾. This document was prepared under the leadership of the Mental Health Action Committee, which was made up of mental health professionals but several stakeholders were involved such as the professional bodies for Psychiatrists, Psychologists, Psychiatric Nurses, Social workers and Occupational therapists. In addition, associations of people with various disabilities were involved. However, there was no single identified consumer group or Non-Governmental Organisation representing mental health service users. A few consumers participated but they did not participate as representatives of a group.

The 2013 National mental policy recommends the following areas for reform:

- Mainstreaming mental and neurological health within national health, social welfare, education and criminal justice policy.
- Integrating mental and neurological health into the primary care system.
- Strengthening and developing existing systems for human resource development, information and communication.
- Decentralization of specialist mental and neurological health services
- Strengthening management of mental and neurological health services
- Encouraging inter-sectoral partnerships with other key Governmental Organizations (GOs) and NGOs.
- Linking to educational programmes in schools, workplaces, the community and the media.

It is noteworthy that service users were mentioned only once in the document. However, there are roles for the service users even though the policy does not specifically assign any roles. Therefore, it would be useful for the proposed mental health plan to specifically assign roles to mental health service users.

2.5. Nigerian Mental Health legislation

Nigeria has no modern mental health legislation. The country still relies on outdated laws from 1916, amended in 1958, inherited from Britain when Nigeria was a British colony. According to a recent review, Nigeria has no functional federal mental health laws at the moment, this is because the Lunacy Act of 1916 as amended by the Lunacy Act of 1958 was not included in the laws of the federation 2004. However the laws are found in the various statutes of the states as state lunacy laws⁽²⁹⁾.

The lunacy acts of 1958 dealt largely institutionalization and compulsory treatment. It did not have any provision for defending the rights of the patient, neither did it regulate the mental health practitioner or protect them from undue litigation. In fact the name of the act is stigmatizing and demeaning. The result of this is that the dignity of the patient is not guaranteed by law, neither are their rights respected.

Attempts to pass modern mental health legislation which meets internationally accepted guidelines as contained in the WHO Checklist for mental health legislation have so far failed. In 2004, a proposed act sponsored by a psychiatrist (Senator Martins-Yellow) and a physician (Senator Dalhatu Taffida) passed through the Senate but did not pass through the house of representatives, which is the lower chamber in Nigeria's bicameral parliament. Again in 2013 a draft legislation was tabled for public hearing by the House of Representatives, but it was not passed.

Neither of the attempts to draft or pass modern legislation had the involvement of any consumer groups, nor was there any outcry from consumers to protest the non-passage of the bill.

2.6. Stigma and Discrimination in Nigeria

Stigma and discrimination against people with mental disorders is rife in Nigeria. It is a well recognised fact that stigma is a barrier to the provision of adequate mental health services. It is also a barrier to accessing the existing services.

A few examples of findings on a community survey in South-Western, Nigeria of stigma towards mental illness include the following⁽⁵⁾:

Respondents views about mentally ill persons:

45.0% of Respondents feels mental illnesses can be treated outside the hospital.

91.5% of Respondents tend to them to be mentally retarded.

95.2% of Respondents see them as a public nuisance.

Only 25.5% of Respondents feel they can work in regular jobs.

96.5% feels mentally ill individual are dangerous of violent behaviour.

Attitude of respondents towards individuals with mental illness

82.7% of Respondents are afraid to converse with mental ill persons.

78.1% of Respondents would be upset/disturbed to work with mentally ill individuals.

81.2% are unwilling to share a room with a mentally ill individual.

82.9% of Respondents will be ashamed if a family member was known as mentally ill.

16.9% of Respondents could maintain friendship.

Only 3.4% of Respondents could marry a mentally ill person.

These findings indicate a pervasive attitude of stigma towards people with mental illness. This stigmatising attitude did not vary significantly even when people had knowledge of the causes of mental illness(30).

Therefore, stigma is a major factor to be considered when planning for mental health services. It might also be an important factor preventing mental health service users from coming together to form consumer groups.

2.7. The role of Consumer and Family Support Groups Worldwide

A review of the activities, roles and functions of consumer/support groups was undertaken to highlight their relevance and contribution to improved mental health. The information is taken verbatim, obtained from the various websites of the referenced organisations.

A brief review of the World Federation for Mental Health whose membership is made up of professionals, consumers and other support groups and organisations is also included.

2.7.1 National Alliance on Mental Illness (NAMI)⁽³¹⁾

The National Alliance on Mental Illness (NAMI) is a nationwide grassroots advocacy group, representing families and people affected by mental disorders in the United States. NAMI provides psycho-education, research and support for people and their families impacted by mental illness through various public education and awareness activities. The National NAMI organization is based out of Arlington, Virginia.

NAMI is organized further into State and Local affiliates, all operating mainly with the work of thousands of volunteers. Members of NAMI are typically consumers of mental health services, family members, and professionals working together toward a common goal. There are over 1,000 NAMI chapters, represented in all 50 states. NAMI has 9 signature programs, many which have been shown to be efficacious in research studies.

NAMI works to keep family safety nets in place, to promote recovery and to reduce the burden on an overwhelmed mental health care delivery system. The organization works to preserve and strengthen family relationships challenged by severe and persistent mental illness. Through peer-directed education classes, support group offerings and community outreach programs, NAMI's programs and services draw on the experiences of mental health consumers and their family members. Members learn to successfully manage mental illness and are trained by the organization to help others do the same. In addition, NAMI works to eliminate pervasive stigma, to effect positive changes in the mental health system and to increase public and professional understanding about mental illness.

2.7.2 World Fellowship for Schizophrenia and Allied Disorders⁽³²⁾

The World Fellowship for Schizophrenia and Allied Disorders (WFSAD) is the only global grassroots organization dedicated to lightening the burden of schizophrenia and other serious mental illnesses for sufferers and their families. It strives to increase knowledge, understanding and compassion and reduce the fear, stigma, discrimination and abuse that accompany these difficult conditions. WFSAD and its member organizations focus on the humane treatment of people with schizophrenia and other serious mental illnesses and on their primary care, which falls frequently upon the family, most often the parents, and can last a lifetime.

WFSAD was founded in Toronto in 1982 by representatives from several established national family organizations. It was incorporated in 1986 and received charitable status from Revenue Canada in 1987.

Its vision is to let families and individuals with schizophrenia and allied disorders live meaningful and productive lives without discrimination, while its mission is to support and empower families through development of family self-help, education and advocacy. Since its inception, The World Fellowship for Schizophrenia and Allied Disorders has been an organization made up of volunteers. Two paid staff and several volunteers assist at WFSAD's office in Toronto, Canada. WFSAD has a very active Board of Directors who support families around the world who are no more than 15 members. Each member does field work in the area assigned to him/her. Thus, the board is a very active, hands-on part of the organization.

2.6.3 European Federation of Families of People with Mental Illness (EUFAMI)⁽³³⁾

The European Federation of Families of People with Mental Illness (EUFAMI) is an international non-profit organisation registered in Belgium that primarily advocates on behalf of carers. It was founded in 1992 after a meeting where members from all over Europe "shared their experiences of helplessness and frustration when living with someone with severe mental illness". The organisation is active in lobbying European Union bodies on behalf of its member organisations. It has members in 26 European countries and one non-European country. It is a federation of 41 family associations (including two non-European ones) and 5 other mental health associations.

EUFAMI is working with GAMIAN-Europe to find support for a European Parliament Written Declaration on mental health and asylum seekers. A Written Declaration is a tool that Members of the European Parliament have to underline their interest in and the need for action for a certain topic. It needs the support of the majority of Members (376 signatures) in order to become adopted as a formal Parliamentary document.

This Written Declaration was prepared as it is felt that there is too little awareness of and attention for the mental health risks and challenges faced by asylum seekers being traumatized by the situation they are fleeing from, the threats and horrors faced on their journey to the destination countries and the rejection and lack of inclusion and opportunities (in many cases) when arriving in their destination countries. Policymakers across the EU aware should be more of the fact that this is a real and serious issue which needs to be taken into account in any effort to address the situation of asylum seekers and their integration in their host countries and communities.

2.6.4 World Federation for Mental health⁽³⁴⁾

The World Federation for Mental Health (WFMH) is an international, multi-professional Non-Governmental Organization (NGO), including citizen volunteers and former patients. It was founded in 1948 in the same era as the United Nations (UN) and the World Health

Organization (WHO). It aims to prevent of mental and emotional disorders, to proper treatment and care of those with such disorders, and to promote mental health

The Federation, through its members and contacts in more than 94 countries on six continents, has responded to international mental health crises through its role as the only worldwide grassroots advocacy and public education organization in the mental health field. Its organizational and individual membership includes mental health workers of all disciplines, consumers of mental health services, family members, and concerned citizens at its very outset the WFMH was concerned with educating both the public and influential professionals, and with human relations, with a view both to the health of individuals and that of groups and nations.

The WFMH founding document, "Mental Health and World Citizenship", understood "world citizenship" in terms of a "common humanity" respecting individual and cultural differences, and declared that "the ultimate goal of mental health is to help [people] live with their fellows in one world Members include mental health service providers and service users. For many years after its founding, the WFMH was the only NGO of its kind with a close working relationship with UN agencies, particularly the WHO. In recent decades, though, a number of international mental health organizations, often limited to members of particular professions, have developed. In varying degree they have filled needs formerly addressed mainly by WFMH. The WFMH envisions a world in which mental health is a priority for all people. Public policies and programs reflect the crucial importance of mental health in the lives of individuals. The first Director General of the WHO, George Chisholm, who was a psychiatrist, was one of the leaders in forming the federation with the goal of creating a representative organization that could consult with the UN on mental health issues.

The mission of the World Federation for Mental Health is to promote the advancement of mental health awareness, prevention of mental disorders, advocacy, and best practice recovery focused interventions worldwide. Mental health day is celebrated at the initiative of the World Federation of Mental Health and WHO supports this initiative through raising awareness on mental health issues using its strong relationships with the Ministries of health and civil society organizations across the globe. Mental Illness Awareness Week (MIAW) is an annual national public education campaign designed to help open the eyes of Canadians to the reality of mental illness. The week was established in 1992 by the Canadian Psychiatric Association, and is now coordinated by the Canadian Alliance on Mental Illness and Mental Health (CAMIMH) in cooperation with all its member organizations and many other supporters across Canada.

CHAPTER 3

METHODOLOGY

3.1 Study design

The study is a descriptive cross sectional study conducted by the use of questionnaires.

3.2 Study setting

The study was conducted by use of email interview questionnaires sent to Psychiatrists all over Nigeria, to capture the Federal Psychiatric facilities to enquire about the existence of consumer groups.

Having identified only one group in Ibadan, southwest Nigeria, further study was conducted in Ibadan.

3.3 Study Instruments

Three questionnaires were used in the study. Two of the questionnaires were purposely designed for this study and the questions were compiled by the researcher based on the information being sought to fulfil the aims of the study. A third questionnaire was modified from a study of consumer groups in New Zealand.

1. *Questionnaire to colleagues working in Psychiatric Facilities in Nigeria.*

This questionnaire was designed to find out about the existence or not of a consumer/family support group in the hospital where the respondents were employed.

The questionnaire also sought to find out about the perceived desirability of having a consumer/family group in their hospital or community, as well as proposed priorities for such groups, were they to be in existence.

2. *In depth interview questionnaire for the facilitator of the identified consumer/family group.*

This questionnaire was modified from the one used in compiling the profiles of organisations included in The Stock Take & Needs Assessment of Consumer Organisations, Groups and Individuals with Advisory & Representative Roles in the Health & Disability Sector in New Zealand⁽³⁵⁾.

It was filled by the facilitator of the group. It provided insight about the vision of the organisation, how the organisation is run, what is their perceived role, etc.

3. *The User Support group questionnaire for service users of mental health facilities.*

This questionnaire was compiled for use in this study when the initial concept was to study all consumer groups identified by email questionnaire. As there was only one consumer group identified by email questionnaire and telephone enquiry, the

questionnaire was administered to members of the identified group. It was also translated into Yoruba which is the local language in South West Nigeria.

3.4 Ethical considerations

Ethical approval was obtained from The National Hospital Ethical Board which has Federal-wide authorization. All Participants were given the option of refusal to participate, after the study had been explained to them.

3.5 Data collection

The questionnaires were completed by the respondents or by trained interviewers who administered the questionnaires as interviews.

3.6 Data Analysis

Statistical methods and analysis

Data entry, cleaning and analysis were done using the SPSS version 20. Descriptive statistics such as means and standard deviations were used to present quantitative variables while categorical variables were presented with proportions and percentages. Attempts were made to compare proportions, to investigate associations among variables and to compare mean difference between groups of variables using parametric and non parametric statistics. All analyses were carried out at 5% level of significance.

CHAPTER 4

RESULTS

4.0 Introduction

This chapter reports the results of the study. The study was conducted using three different questionnaires targeted to obtain the information required to attempt to answer the research question.

4.1 Survey of Psychiatric hospitals and facilities in Nigeria

Questionnaires were sent by email to 28 Psychiatric facilities in Nigeria to enquire about the existence or lack of a consumer/family support groups. Of these, email responses were obtained from 13 of them. In addition, 6 of the non-responding institutions were reached by phone and they reported that they did not have consumer groups in their hospitals, although they were unable to deepen the conversation by answering the questionnaire completely.

Two hospitals reported that they have consumer groups, namely University College Hospital Ibadan and Federal Neuropsychiatric Hospital Maiduguri. The group in Maiduguri was not available for survey because of the insurgency going on in the north eastern part of Nigeria.

The results of the preliminary survey are show in Figure 1- and Tables 1- 2.

Figure 1- Geopolitical Distribution of Hospitals surveyed all over Nigeria

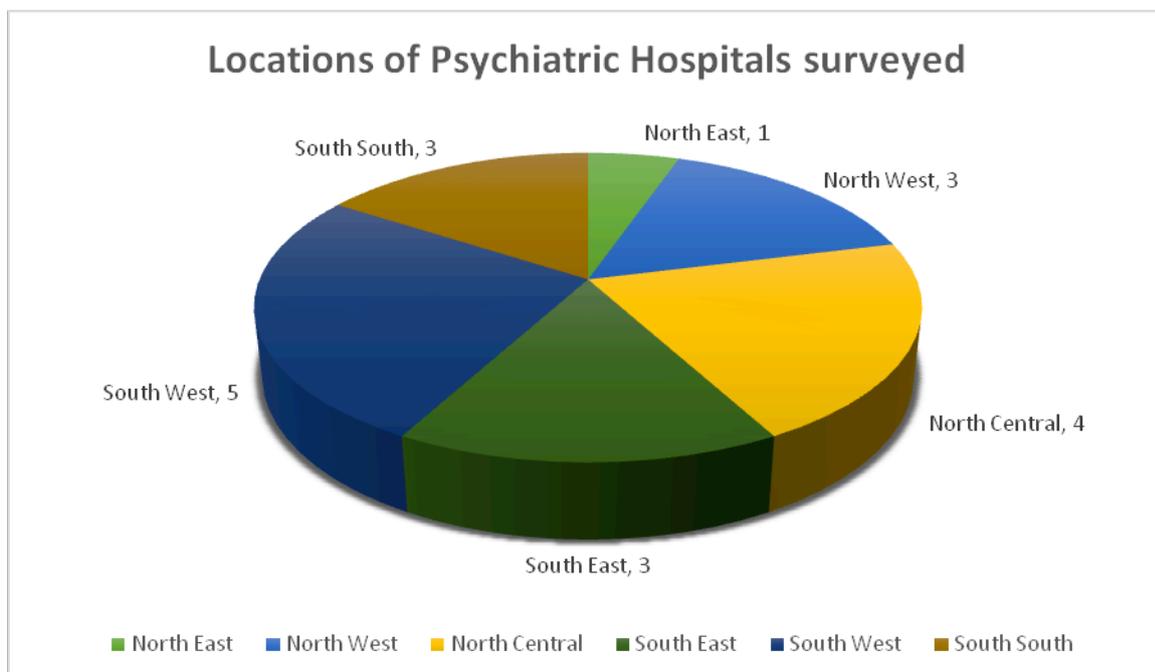


Figure 1 shows that the survey of hospitals covered the whole country. Nigeria for purposes of economic and political administration. Federal Psychiatric facilities within each geopolitical zone. A total of 13 hospitals were fully surveyed, whilst 6 were partially surveyed. Their distribution nationwide shows that there was no zone left out.

Figure 2 shows the answer to the question of whether or not there exists a functioning group in the hospitals surveyed. Only 2 out of 19 hospitals had a consumer group.

FIGURE 2 Mental Health Consumer Groups Functioning under the auspices of hospitals surveyed

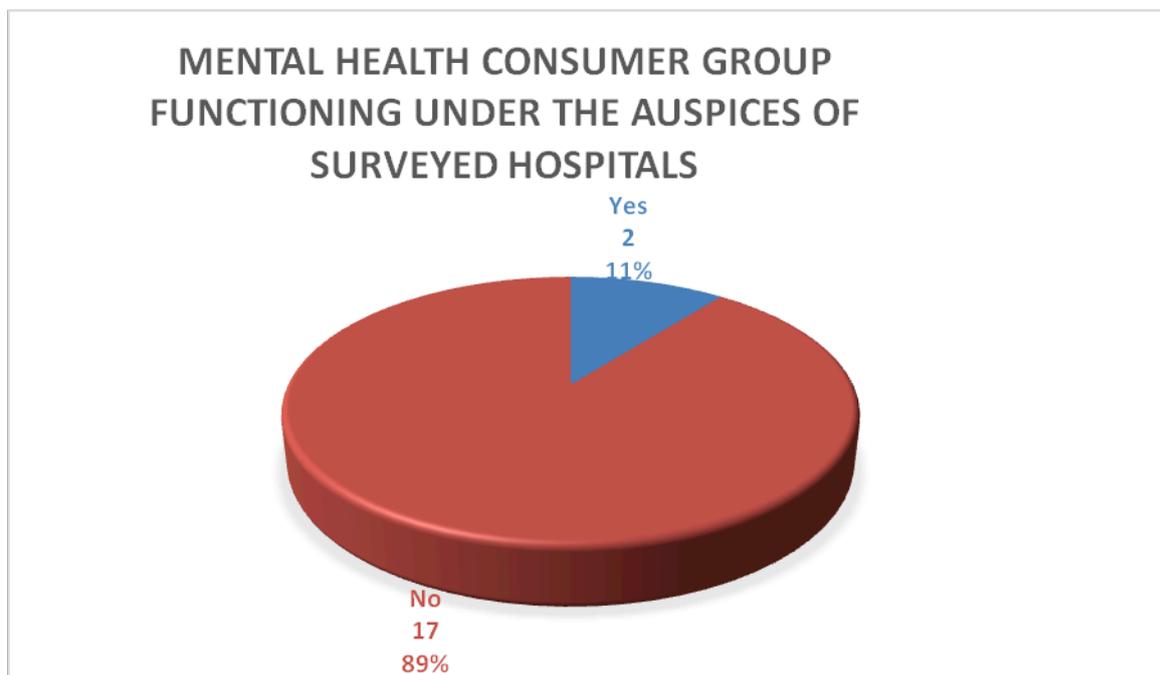


Table 1 shows the same information in figure 2. In addition, it shows the reasons why the group stopped functioning and plans in establishing a group

TABLE 1 Preliminary findings about functioning of consumer groups in Nigerian hospitals.

Variables	n	%
Ever had a group that is no more functioning?		
YES	1	(7.69)
NO	12	(92.3)
Reason why the group stopped functioning	We have a consumer group among patients with epilepsy currently functioning but other consumers/family groups stopped functioning years back largely due to lack of political will by policymakers to organize the consumers/family groups & lack of initiative from the patients/family group	
If you have never had a consumer/family group, are there plans to establish one?	n	%
YES, DEFINITELY		
YES, PROBABLY	1	7.6
NOT LIKELY	5	38.5
DEFINITELY NOT	0	0
NOT SURE	0	0
Not Applicable	5	38.5
	2	15.4

TABLE 2: Practitioners' attitudes towards the establishment of consumer groups

Variables	n	%
Desire to have consumer/family groups for mental health in your HOSPITAL		
HIGHLY DESIRABLE	8	61.5
DESIRABLE	5	38.5
PROBABLY NOT	0	0
DEFINITELY NOT	0	0
NOT SURE	0	0
Importance of having consumer/family groups for mental health in your COMMUNITY(practitioners)		
HIGHLY IMPORTANT	7	53.8
IMPORTANT	5	38.5
PROBABLY NOT	0	0
DEFINITELY NOT	0	0
NOT SURE	1	7.7
Willingness to be part of an effort to start such a consumer/family group in the Community		
YES, DEFINITELY	11	84.6
YES, PROBABLY	1	7.7
NOT LIKELY	0	0
DEFINITELY NOT	0	0
NOT SURE	1	7.7
Preferred venue for consumer group meetings (practitioners)		
COMMUNITY	9	69.2
HOSPITAL	4	30.8

BOX 2. Desired activities for proposed Consumer/Family groups (Practitioners)

- Supporting one another emotionally--8(61.5)
- Sharing and receiving information about mental health--8(61.5)
- Education of the public--8(61.5)
- Education of hospital staff--6(46.2)
- Advocacy to government--7(53.8)
- Advocacy to the hospital management—6(46.6)
- Bulk purchase of drugs--4(30.8)
- Establishment of community mental health facilities--5(38.5)
- Establishment of other consumer groups like yours--4(30.8)
- Participating in research--4(30.8)

BOX 3: Four activities considered most important for Consumer Groups (Practitioners)

- Sharing and receiving information about mental health
- Supporting one another emotionally
- Education of the public
- Advocacy to government

BOX 4: Other useful comments you may wish to make to further enrich this interview

I think it would be helpful to know how much care providers value the consumers, accord them dignity & are willing to have them (consumers) have a voice in service delivery, from planning to implementation

4.2 A description of the Ibadan Consumer/Family Support Group

The single identified functional consumer/family group from this study was found to be located in Ibadan, South-West Nigeria. The name of the group is called Family Support Group. The information to provide this description comes from an in depth interview with the facilitator of the group.

4.2.1 About the Group and the Services it provides

Information about the Family Support was obtained from a social worker who facilitates the activities of the group. He is a member of Staff of a research Project domiciled within in the department of Psychiatry, University of Ibadan. His was a key informant who was interviewed using a modified version of the Stocktake needs Assessment questionnaire which is found as Appendix I.

The Family Support Group was founded in 2008. It focuses on health conditions related to mental and social disability. The group has a total membership of approximately 100 people. It has no legal status as it is not yet a registered body and it has no office of its own. It operates out of a research office in the department of Psychiatry, University College Hospital Ibadan, Nigeria. The group has an elected board. It currently has no paid full time staff, but operates with volunteer staff.

Its vision is to:

- Reduce the level of stigmatization.
- Engage government to participate in discussions on mental health.
- Reduce the incidence of relapse among patients.

In the last 12 months, prior to this study, The Family Support group has provided the following services to consumers:

- Provided information and education to consumers.
- Represented consumers' interest or advocated on their behalf.
- Provided health and disability services.
- Provided awareness raising, education or training about consumers' health condition/disability services or consumers' needs.
- Provided awareness raising, education or training about consumers' health condition/disability or consumers' needs
- Provided support and advice to consumer
- Advocacy services.

This group has provided these services to approximately 100 consumers, who are their members, in the last 12 months. Their activities do not focus on any particular Consumer Group identifiable by their Age, Gender and Ethnicity. People of all ages, ethnicity or gender are welcome to join and participate.

4.2.2 Consumer Information and Education provided by the Group

This group has provided the following information and education service in the past 12 months:

- Information and education about how to treat and manage health condition or disability.
- Provided information on how to access health or disability services.
- Provided information on making complaints or providing consumer feedbacks.
- Information and education about the health condition or disability in general.

This group provided information and educational services through the following means:

- Telephone.
- Face-to-face.
- Print media.
- Through third parties e.g. health educators who tell patients about the group.

The group has found these methods of outreach to be all equally effective.

Face-to-face communication has been used to:-

- Visit consumers in their homes.
- Attend or make contribution at support meetings.
- Attend and make presentations at consumer group expos or other similar gatherings
- To attend or make presentations at conferences.

The Family Support Group in the last 12 months has used paid consultants to provide General information to its members.

The greatest assistance to this group in terms of its ability to provide information and education service to consumers are:

- It has reduced the incidence of relapse.
- It has increased the knowledge about mental illness

In terms of its ability to provide information and education service to consumers, the Family Support Group plans to invest in general information, in order to build its capacity over the next 12 months. The greatest barrier facing this group in terms of the provision of information and education services to consumers in general are:

- Poor funding.
- The mental health bill that has not been passed.

4.2.3 Consumer Representation and Advocacy provided by the Group

In the last 12 month, the Family Support Group has represented consumers' interest and advocated on their behalf in areas such as cost of health and disability services which will be likely advocated on in the next 12 months.

Family support group advocated to the following in the last 12 months:

- Government officials in the Ministry of Health.
- Local government Chairmen and Councilors.
- Hospital board.

Family support group used the following methods to advocate:

- Direct advocacy and negotiation.
- Media presence e.g. radio shows.

Family Support Group has carried out this advocacy in the last 12 months using Voluntary staff.

4.3 A Study of the Ibadan Family Support Group.

4.3.1. Demographic data of a sample of members of the Ibadan Group

Table 3 shows the distribution of the demographic characteristics of the regular participants. The total number of respondents was 42 and they were predominantly women (54.8%). There was a preponderance of married over single respondents (n=32, 76.2% vs. n=6, 14.3%). The distribution between skilled and unskilled workers showed that the first ones represented 52.4%, while the latter 47.6%. Finally, more than half of the respondents were family members or carers (52.4%) compared to those who were themselves the patients (47.6%).

Table 3 Demographic characteristics of Family Support Group respondents (n=42)

Characteristics	n	Percent
Sex		
Male	19	45.2
Female	23	54.8
Age		
<30yrs	2	4.8
31-45yrs	16	38.1
Valid 46-60yrs	13	31.0
60 & above	11	26.2
Years of Schooling		
0	4	9.5
1-6yrs	9	21.4
7-12yrs	15	35.7
13yrs & above	14	33.3

Marital status		
Single	6	14.3
Married/cohabiting	32	76.2
Divorced/separated	4	9.5
Occupation		
Skilled	22	52.4
Unskilled	20	47.6
Category of service users		
Self	20	47.6
Family member/caregiver	22	52.4

4.3.2 Membership drive, regularity of attendance and overall perception of the group

Table 4 shows how the members of the Family Support Group got to learn about the group, how long they have belonged to the group, how many times they attended meetings of the group in the past year prior to the survey and their overall perception of how beneficial they felt their membership of the group has been.

As shown in Table 4, the majority (59.5%) learned about the Group through the Psychiatry clinic, followed by personal approach by a staff member and a friend (19% each). Most of the respondents had become members of the Group for more than one year (95.2%), attended the meetings more than 6 times in the last year (90.5%), and thought the Group highly beneficial (95.2%).

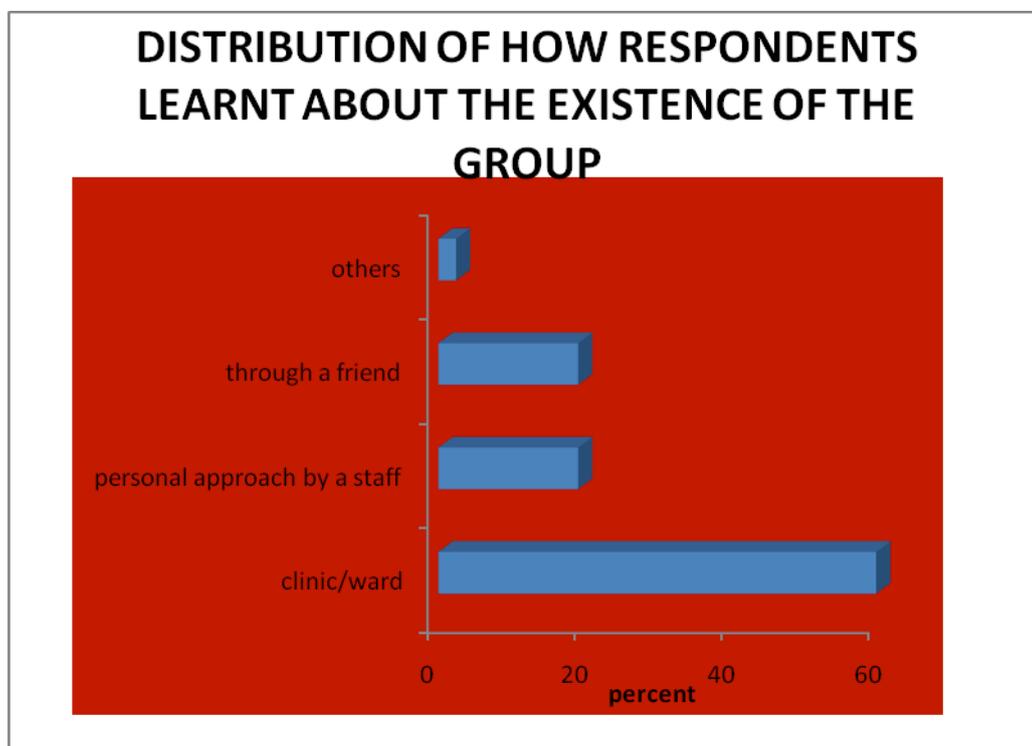
Figure 3 is a bar chart showing the distribution of how respondents learnt about the existence of the group. It shows that most members were recruited by face to face contact.

Table 4 Family Support Group respondents' participation in the Group (n=42)

How they learned about the existence of the Group	N	%
Clinic/ward	25	59.5
Personal approach by a staff member	8	19.0
Through a friend	8	19.0
Flyers/handouts	-	-
Text message	-	-
Others	1	2.4
Duration of membership		
<1year	2	4.8
1 year/more	40	95.2
Attendance in the last 1year		
0	-	-
1 time	-	-
2-5 times	4	9.5
6-10 times	17	40.5
>10 times	21	50.0

Belief that the group is beneficial		
Highly beneficial	40	95.2
Beneficial	1	2.4
Not so beneficial	1	2.4

Figure 3. Means by which members learnt about Family Support Group



4.3.3. Reasons for attending meetings of the Group

Members of Family Support Group were asked to rate the importance each item on a list of possible reasons for attending the group meeting. The results, shown in Table 5 indicate that members felt it was highly important to attend meetings so as to talk to others who belong to support groups, learn more about why/how mental illness happens (70.7), get support to make some changes in respondents'/relative's life (70%), to understand respondents/ relative better (61.5%), to Feel better about oneself (90.0%) and to finding out where to get help (69.2%).

Table 5: Reasons for attending Family Support Group meetings

Reasons for attending support groups	N	Percentage
Talking to others who understand my situation		
Highly important	29	70.7
Important	11	26.8
Not so important	1	2.4
Definitely not important	-	-
Not sure	-	-

Information about counseling options		
Highly important	18	43.9
Important	18	43.9
Not so important	4	9.8
Definitely not important	-	-
Not sure	1	2.4
Learning more about why/how mental illness happens		
Highly important	29	70.7
Important	10	24.4
Not so important	2	4.9
Definitely not important	-	-
Not sure	-	-
Support to make some changes in my life/my relative's life		
Highly important	28	70.0
Important	8	20.0
Not so important	2	5.0
Definitely not important	1	2.5
Not sure	1	2.5
Understanding myself/my relative better		
Highly important	24	61.5
Important	14	35.9
Not so important	1	2.6
Definitely not important	1	2.6
Not sure	-	-
Feeling better about myself		
Highly important	36	90.0
Important	3	7.5
Not so important	-	-
Definitely not important	1	2.5
Not sure	-	-
Finding out where to get help		
Highly important	27	69.2
Important	10	25.6
Not so important	2	5.1
Definitely not important	-	-
Not sure	-	-
Feeling more hopeful about my life		
Highly important	32	76.2
Important	8	19.0
Not so important	1	2.4
Definitely not important	1	2.4
Not sure	-	-

4.3.4 Perceived benefits of belonging to the Group

As shown in Table 6, although most respondents (83%) felt equally comfortable talking to either an individual or talking in a group, they identified specific benefits of belonging to the Family Support Group. The majority (88.1%) referred to getting useful health information,

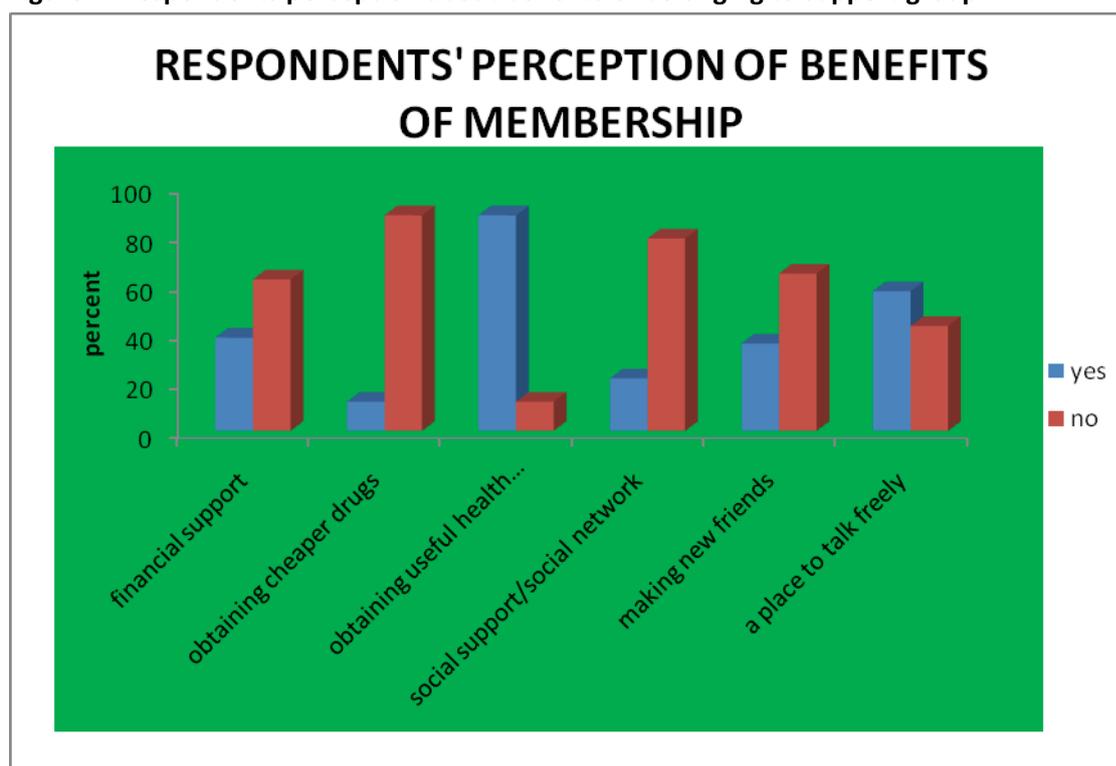
followed by have a place to freely about their health concerns (57.1%). Other benefits endorsed were financial support (38.1%) and making new friends (35.7%).

The results appear in Table 6 and Figure 4 below

Table 6. Benefits of participating in the Group

Most comfortable with	N	%
With other users with similar experiences	5	11.9
Conversation with only one person	2	4.8
Both	35	83.3
Which support have you benefitted from		
Financial support	16	38.1
Obtaining cheaper drugs	5	11.9
Obtaining useful health information	37	88.1
Social support/Social Network	9	21.4
Making new friends	15	35.7
A place to talk freely about our health concerns	24	57.1

Figure 4. Respondents perception about benefits of belonging to support group



4.3.5 Regrets about belonging to The Group

As shown in Table 7, although as expected, the majority of the respondents found it beneficial to belong to the Family Support Group, they were also asked to indicate if they

had any regrets or reservations about belonging and if so, to specify. The large majority (92.9%) had no regrets.

Table 7. Regrets/Reservations about belonging to the Group

Regrets/Reservation about belonging to the Group	n	%
No	39	(92.9)
Yes	3	(7.1)

Of the 3 respondents who indicated regrets, only one specified the regret as follows (verbatim quote): in Box 5

Money given is too little. Please seek help from wealthier ones in society to help the organisation.

Box 5: Regret about belonging to the group

4.3.6 Perception about location of Support Group meetings

The respondents were asked to comment on the preferred location of the group meeting. Their responses are as shown in Figures 5 and 6. The majority believed that having the consumer/ family group for mental health in their community was highly important (66.7%), followed by those that thought it was important (19%). However, most respondents (92.9%) preferred to attend the meetings in the hospital rather than in their community.

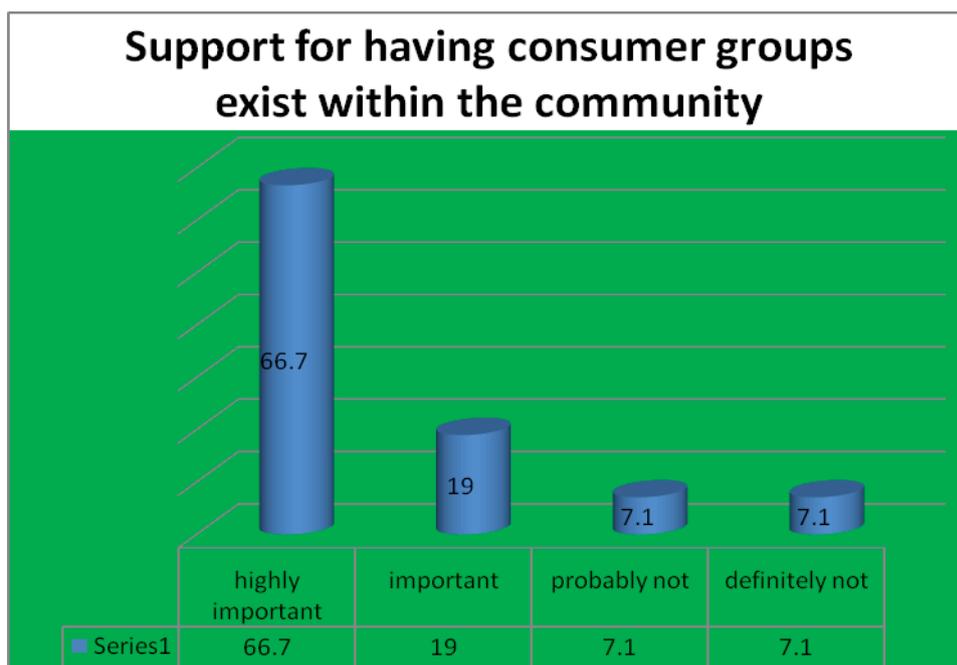


Fig 5 Respondents views about having mental health consumer groups in their Community

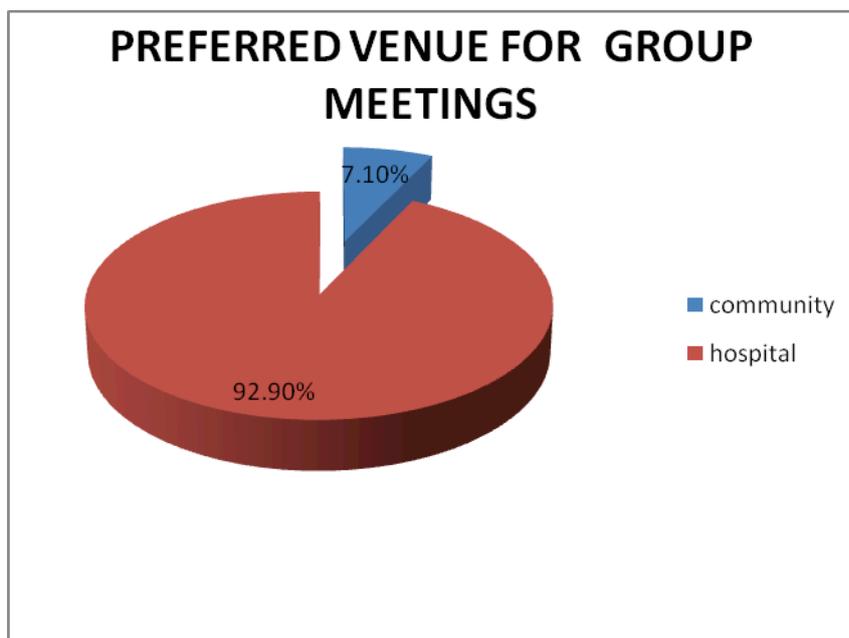


Figure 6 Respondents' preferred venue to attend consumer group meetings

4.3.7 Activities of the Group actual and desired.

Respondents were asked about the current activities of the group and to mention activities which they desire for the group to engage in. As shown in Tables 8 and Box 5, the majority of the respondents (61.9%) thought that sharing and receiving information about mental health was important, followed by supporting each other emotionally (37.5%).

Table 8. Areas of activity of the Family Support Group

Areas of activity of the Consumer/Family Group	N	%
Sharing and receiving information about mental health	26	61.9
Supporting one another emotionally	15	35.7
Participating in research	5	11.9
Education of the public	2	4.8
Education of hospital staff	1	2.4
Advocacy to government	1	2.4
Bulk purchase of drugs	1	2.4
Establishment of community mental health facilities	1	2.4
Establishment of other consumer groups like yours	1	2.4
Advocacy to the hospital management	-	

Box 6 lists the activities that respondents endorsed the most frequently as being important.

Box 6: Activities considered to be most important by consumers

- Sharing and receiving information about mental health
 - Supporting one another emotionally
 - Participating in research**
 - Education of the public*
- ** only 11.9% endorsing * only 4.8% endorsing

Listed below in Box 7 are the activities

respondents would like to engage in which are yet to commence. This would suggest the direction which the members foresee for future expansion of FSG's activities.

BOX 7

- Help in purchasing drugs cheaper or giving drugs free of charge.
- Help in providing employment for patients on treatment, those who have recovered and for the family members who take care of them.
- Reach out to the government for recognition and more involvement.
- Create public awareness about mental health issues on television and radio.
- Making visits to members communities.
- Printing programs in Yoruba (the local) language.
- Stimulate formation of support groups in all primary health care centres.
- Allow members to participate as researchers.
- Provision of a stipend for the secretary of the association.
- Holding meetings on clinic days.
- Members to be given priority to see Doctors in clinic.

Box 7: Activities respondents would like to see the group engaged in which have not yet commenced

CHAPTER 5

DISCUSSION

5.0 Introduction

This study evaluated the role of consumer and family groups and their potential contribution to mental health policy and services in Nigeria. The findings from the study are discussed in this chapter here in the context of the roles and activities of other consumer groups, especially in terms of their potential. The strengths, limitations and implications of the study findings for policy, practice and future research are also presented.

5.1 Thesis findings in context

5.1.1. Survey of Psychiatric hospitals and facilities in Nigeria

Although 28 Psychiatric facilities were reached, including by phone calls, only 19 responded. However, the 19 covered all the different parts of the country as shown in Figure 1. Further informal enquiry did not reveal the existence of any consumer support group outside of the nominal two identified in the initial survey. This confirms the finding incidentally discovered by this researcher when as Secretary General of the Association of Psychiatrists in Nigeria in 2008, attempts were made to find a consumer group to involve in the stakeholders meetings to prepare for drafting of a revised National mental health policy and not a single consumer group was found nationwide. Apparently this remains the case till 2016.

From the survey, only two psychiatric facilities had consumer groups. One hospital (Maiduguri) could not be studied because of insurgency in that part of the country. For the same reason, it is safe to assume that the group is likely to be non-functional because most activities that are non-essential in the city do not take place due to curfews and restricted movement of persons.

The identified functioning group which was studied belongs to University College Hospital. The Department of Psychiatry of the College of Medicine, University of Ibadan also serves the University College Hospital and is host to a WHO Collaborating Centre for research. The department is the oldest academic department of Psychiatry in Nigeria. It is home to a leading health systems researcher in the country, Professor Oye Gureje and he was the one who galvanized staff as volunteers to start the consumer group called the Family Support Group. For completeness, it should be mentioned that he also discovered there was no support group in 2008 as President of the Association of Psychiatrists in Nigeria during the search earlier mentioned. Therefore, professional leadership may have an important role to play in starting up the initial series of consumer groups until sufficient awareness is created for consumers to fully take over the founding and running of service-user groups.

Of the hospitals that have no consumer group, only one indicated definite plans to start a group. This may be because clinicians working in Psychiatric facilities are already overburdened due to their few numbers compared to the patient load. But it is also may be due

to the fact that the respondents, all Psychiatrists, did not view issues of public mental health as a priority. This is based on answers to the query: although all the respondents thought it was desirable to have consumer groups in their hospitals, yet they did not have plans to start one.

The Psychiatrists mostly opined that it was important to have such groups in their communities and were even willing to be part of the effort to start a group. Indeed, roughly two thirds preferred that the consumer group meetings be held in the community. This is a positive view in terms of the ultimate goal of having consumer groups in the community

The Psychiatrists respondents identified the following as the 4 priority activities for consumer groups:

- Sharing and receiving information about mental health
- Supporting one another emotionally
- Education of the public
- Advocacy to government

These responses appear to imply that the clinicians did not seem to believe that it should be the priority of consumer groups to engage in activities that might directly affect services in the hospital or their own clinical practice. Although this sample size is small, the results showed that less than 50% of respondents endorsed the following as priority areas for consumer groups:

- Education of hospital staff--6(46.2%)
- Advocacy to the hospital management--6(46.6)
- Bulk purchase of drugs--4(30.8)
- Establishment of community mental health facilities--5(38.5)
- Establishment of other consumer groups like yours--4(30.8)
- Participating in research--4(30.8)

This area will require further research because it would be important to ascertain the attitude of service providers to the (proposed) activities of consumer groups. This is also important because given the largely paternalistic stance of current medical practice in Nigeria, practitioner support for advocacy groups at least at the initial stage could be highly relevant is determining the take off and growth of consumer groups and in helping them to shape their focus.

5.1.2. The Family Support Group (FSG) in the light of the objectives of this study.

This study set out to enquire about any active consumer groups in Nigeria with defined objectives. The results obtained which are reported in Chapter 4, will be discussed in the light of these objectives.

5.1.2.1 Current state of the Group and its evolvement.

Founded in 2008, FSG has remained active since then. Although run purely by volunteers, it is facilitated by a paid staff of a mental health research project based in the hospital., assisted by other staff members and members of a board elected from among the members.

From a small group that held monthly meetings, the FSG expanded and now has two groups of approximately 50 members each, meeting monthly.

The methods of outreach which the members found to be most effective were:

Information received by health care worker from the Clinic or ward, Personal approach by a staff member and through a friend.

These relatively inexpensive face to face methods seemed to work better for members, even though the facilitator reported that print media, telephone and face to face methods were equally effective.

FSG has a three-point vision

- Reduce the level of stigmatization.
- Reduce the incidence of relapse among patients.
- Engage government to participate in discussions on mental health.

The members considered the following to be the most important for the group:

- Supporting one another emotionally
- Sharing and receiving information about mental health

Members endorsed the following as their most important reasons for attending meetings:

- Talking to others who understand my situation
- Learning more about why/how mental illness happens
- Support to make some changes in my life/my relative's life
- Understanding myself/my relative better
- Feeling better about myself
- Finding out where to get help
- Feeling more hopeful about my life

The benefits of belonging to the group endorsed most by the members were:

- Obtaining useful health information
- A place to talk freely about our health concerns

It would appear that the group's activities, the reasons for which members attend meetings and the perceived benefits of their attendance all fit within the first two points of the group's vision. This is very positive for the growth and sustenance of the group.

Membership of the group meets the members' need for coping with the emotional burden of mental illness, which perhaps may not be sufficiently addressed in Nigeria's present day over-burdened and under-staffed mental health care system.

It is also a useful outlet of helping members obtain correct information about mental health conditions. This is another significant role which mental health consumer groups can easily fill. Indeed when it comes to sharing the living experience of mental illness. Only consumer and family groups can authentically fill such a role because those who have never experienced mental illness can only at best, imagine what it entails.

In reality therefore, by supporting one another, in the ways indicated by the respondents, the benefits to the members and the health care services, based on their current activities, include:

- Providing psycho-education and real shared experience
- Providing an empathic listening ear and giving practical advice for coping based on experience.
- The relief to talk freely about their mental health conditions in a non-stigmatising environment.
- Encouragement to persevere with treatment, thus improving follow up clinic attendance and drug compliance.
- Reducing expressed emotion since the members have a forum to share even their most frustrating experiences, whilst learning from those of others.
- All the above contribute to reducing the relapse rate which would reduce the economic and psychological burden on members and reduce the burden on the mental health care system.

In addition to the above-listed benefits, there are potential benefits that could accrue to the health care system even from the current activities of the group:

- Education of the public could improve outreach to people with mental illness and their families, most of whom are currently outside of the mental health care system, considering the huge treatment gap in Nigeria.
- Education of the hospital staff has the potential to improve the quality of care by sharpening the personal skills and improving the attitude of staff. Although this was not endorsed by many members, it is important to remember that we all learn every day and learning is a two-way street. Learning from patients and their families would improve staff regard for the consumers, which would boost patient confidence and promote service utilization.

- Advocacy to hospital management would be of great benefit to both service users and mental health staff. This is because in Nigeria, as in other LAMICS, the Psychiatric hospitals need to be more user-friendly. The advocacy to hospital management could improve humane treatment and respect for human rights. It has been documented in the literature that when patients have to remain in long stay facilities, consumer engagement is recommended to prevent human rights abuses⁽³⁶⁾. Also in general hospital settings e.g. teaching hospitals, where mental health services are situated within a department of Psychiatry, such departments are often treated as “Cinderella” departments which receive minimal funding and attention even to ward and clinic facilities. Therefore, consumer advocacy could bring about the needed attention and improvement.
- Bulk purchase of drugs is another potential benefit which the group could enjoy, particularly in the poor economy where patients have to pay cash up front, out of pocket for services and drugs. In addition, the hospitals tend to stock only the drugs on an essential list which therefore limits access to more modern medication for the significant minority who need it. Although the hospitals would rather not lose revenue by selling drugs cheaper, a mutually agreeable and beneficial arrangement can be reached as long as some form of engagement occurs between the consumer groups and hospitals /pharmaceutical companies.
- Establishment of community mental health facilities was endorsed by one person and may not be actually happening yet. But there is a huge potential role for consumer groups to participate in scaling up services. For example, in introducing the mhGAP, the WHO stated “Civil Society including service users, caregivers, and family members are key partners for improving services. The involvement of users/patients and their caregivers is an important aspect of the care and treatment extending across health and social care.”⁽¹⁸⁾
- Participating in research an important potential for improving services and even policy. It is useful to have consumers and their families as participants, such as in the present study. But it is equally useful to have the consumers as researchers and to encourage consumer-driven research⁽⁷⁾⁽³⁷⁾.

5.1.2.3 Members’ role and potential in mental health policy formation and legislation.

It is significant to note that none of the members endorsed advocacy to government as an activity of the group, although some of them mentioned it as an activity they would like to see the group engaged in which has not commenced.

Conversely, the facilitator of the group endorsed advocacy to government and specified some activity.

The implication of this is that it is possible for the executive board of the Group to have been taking some steps in advocacy without involving the entire group. Whilst this may be a necessary initial step, it would probably not be the best way forward.

Without making assumptions about the case in point, it is well documented that consumer groups can be powerful advocates to government, for the purpose of policy formulation and implementation and to advocate for good legislation⁽⁸⁾.

The mental health system in Nigeria needs strong advocacy to pass its proposed mental health legislation which has suffered from failed attempts so far and at present is not even under consideration in the National Assembly.

In addition, implementation of the 2013 National Mental Health Policy has not commenced and strong, focused advocacy from consumer groups would be a positive contribution. Even though Nigeria is currently in economic recession, there is an urgent need to scale up mental health services. Since mhGAP was introduced and the Lancet Series were written, Nigeria has had militancy in the Niger delta located in the southern part of the country and insurgency and terrorism in the North East. The result is hundreds of thousands of Internally Displaced Persons, all traumatised and millions more who are vicariously traumatized by the news and events happening around them. In addition, there is also a simmering substance abuse problem as many are abusing alcohol, illicit drugs and prescription medication.

Although the mental health care system is currently stretched to its limit and in need of urgent intervention, the treatment gap if assessed today might in fact have become wider. Therefore, the need for effective advocacy has become even more urgent and necessary.

5.1.2.4 Members' perception of their role.

From the results demographics showed that the respondents were predominantly female (54.8%) with 69.1% between 30-60 years of age. Skilled workers represented 52.4% whilst unskilled workers represented 47.6%. Close to 70% had more than 6 years of education. Finally, more than half of the respondents were family members or carers (52.4%) compared to those who were themselves the patients (47.6%).

From the data above it can be inferred that the group is older, more educated and skilled than the average representative sample. Therefore, they are better likely to understand their roles and responsibilities and articulate their positions.

Members of the group have an understanding of their actual roles and also of their potential roles. Thus there was a fairly long list of activities which the group members desire to see, but which the group was not yet engaged in.

- Help in purchasing drugs cheaper or giving drugs free of charge
- Help in providing employment for patients on treatment, those who have recovered and for the family members who take care of them

- Reach out to the government for recognition and more involvement.
- Create public awareness about mental health issues on television and radio.
- Making visits to members communities.
- Printing programs in Yoruba (the local) language.
- Stimulate formation of support groups in all primary health care centres.
- Allow members to participate as researchers.
- Provision of a stipend for the secretary of the association
- Holding meetings on clinic days.
- Members to be given priority to see Doctors in clinic.

Except for the last two items on the list, this shows a group that is ready to give more support to its members, to engage in educating the public, to replicate itself and to take on advocacy.

5.1.2.5 The Group's achievements so far.

The FSG appears to have made steady progress since inception. That the group has remained in existence and grown its membership over the years and continued to meet monthly is in itself an achievement.

The group has provided information and health education to its members.

The FSG has also sensitized its members and positioned them for higher level of activity, including advocacy.

5.1.2.6 The Group's challenges.

The FSG has financial challenges as reported by the facilitator and mentioned by some respondents.

The group is not registered by the Corporate Affairs Commission and this could be a hindrance to higher achievement in terms of fundraising and engaging interaction with government. For this reason, it is important to register the group as a charity.

5.1.2.7 Assessment of The Group's needs.

The Family Support Group has sustained its activities so far but the tasks ahead are many and will require a well informed and articulate group

Therefore, one important need of the group is training.

The group has specific training needs in the following areas:

- Advocacy skills
- Negotiation skills
- Fund raising skills

- Mobilisation skills

The training can be sourced locally through willing and available professionals who can serve to build up a knowledge base.

Training can also be sourced through collaboration with other health consumer groups with similar challenges that have become well-established e.g. The Albino Foundation, Sickle Cell Foundation, etc.

Finally, training can be sought through collaboration with international mental health consumer groups such as WFSAD, EUFAMI and NAMI. This international collaboration could be largely virtual, taking place via interaction on the internet and social media. Therefore, keeping its costs less expensive.

5.2 Strengths and Limitations of the study

The main strength of this study was that it focused on a subject of public health importance which had not been examined in Nigeria prior to this effort but which could engender further study to galvanise the voice of the consumers that had hitherto remained largely unheard.

The limitations of the study include the following:

Only one group was studied and the results may not necessarily be generalizable to other groups. However, it is hoped that having studied this group, it should be possible to identify strengths and weaknesses so that intending groups will be able learn from this.

5.3 Implications for theory, clinical practice, policy and research

The findings from this study may have implications for theory, clinical practice, policy and research for mental health in Nigeria

Theoretically, the belief has been that due to stigma, people may not come together publicly to identify themselves as mental health service users or families. This study has shown that, in spite of the risk of stigma, this group has been formed and has continued to grow.

In clinical practice, workers in the field of mental health must be familiar with the frustration of knowing that a patient or a family needs psychosocial support in terms of being able to relate with people who have similar problems, yet there is no group to refer them to. This study has shown that it is possible to stimulate the formation of consumer/family groups where members can support one another.

In the event that consumer groups will develop and become a major force for patient empowerment, they may improve clinical practice in that patients would be more articulate and clinicians would be less paternalistic. Rather, clinicians will have to take a more evidence-based approach and clinical practice should be more patient-centred.

For Policy, the findings from this study may indicate that there is great potential for consumer and family groups to be involved in contributing to and influencing policy as happens in the developed economies. So the time has come to rethink policy and incorporate the views and needs of consumers into policy making, implementation and evaluation.

CHAPTER 6

CONCLUSIONS AND RECOMMENDATIONS

Conclusions

The main aim of this thesis was to study the role of consumer and family groups and their potential contribution to mental health policy and services in Nigeria.

This study conducted an email survey of Psychiatrists in Federal Psychiatric facilities all over Nigeria and confirmed the existence of two consumer groups in the country. However, since one (Maiduguri) was located in the North Eastern part of the country where there is ongoing insurgency, with strict security and restricted movement of people, it was only possible to study the group located in Ibadan.

The Psychiatrists were all in favour of the establishment of consumer groups to operate under the auspices of their hospitals and they were even more in favour of locating the consumer groups in the community. The 4 priority areas most endorsed by Psychiatrists which they thought that consumer groups should focus on, were sharing and receiving information about mental health, Supporting one another emotionally, Education of the public and Advocacy to government.

Therefore, it can be concluded that Practitioners showed a good understanding of the roles and potentials of consumer groups. But in spite of this fact, there does not seem to be the impetus on their part to facilitate the establishment of such groups. The reason for this dissonance in recognizing the need, yet not acting to meet that need requires further study.

This study has profiled The Family Support Group, a consumer group operating in Ibadan, South-west Nigeria. The group was found to be a relatively small but vibrant one whose members are enthusiastic as evidenced by their positive statements about the group and their regular attendance of meetings.

The Family Support Group has a three-point vision which is to reduce stigmatization and the incidence of relapse among patients and to engage government to participate in discussions on mental health. From the findings from this study, it can be concluded that the group is doing well in achieving its first two objectives, as evidenced by the level of satisfaction expressed by members of the group.

However, Family Support Group needs to take further steps towards achieving the objective of engaging government. Although this is included in its vision, Advocacy to government did not rank among the top 4 activities which members of the group considered to be the most important. In addition, the group is not yet a registered legal entity and this is a necessary step to enhance its potential ability to engage with government as well as with other corporate sponsors.

Therefore, it can be concluded that the Family Support Group is playing a role in its local sphere of influence by providing a forum where members are able to share and receive information about mental health and support one another emotionally. The group is playing an important role in reducing the felt burden of mental illness among consumers and their families and the extent to which this impacts on services, e.g. by improving clinic attendance, by reducing expressed emotion and ultimately reducing relapse rates are subjects for further research.

Regarding the potential of this consumer group to contribute to mental health policy and services in Nigeria it can be concluded that given the right direction and support, the group has good potential. This is evident from the vision of the group, from the activities the group is engaged in and from the activities that the members of the group have indicated they desire to be engaged in. Given the enthusiasm of the group, it would appear that the group itself would be very welcome to ideas for improvement and for support and training to deepen their scope and broaden the reach of their activities.

Recommendations

Based on the findings from this study, the following recommendations are suggested.

Mental Health workers in Nigeria should be made aware or reminded of the potential role and contribution of consumer and family groups to mental health policy and services in Nigeria. From the literature review, this did not appear to be a subject that has generated much interest in Nigeria to date.

Mental Health workers should be stimulated to explore the possibility of stimulating interested patients and their family members to form consumer groups

The facilitators of the Family Support Group (as well as any other functioning groups discovered or founded) should be commended for their effort in running a consumer group even when it would appear that there is very little institutional support or funding for their activities, but they should be trained to understand the potentials of the group and how best to attain them

The group should be helped to engage in networking with other groups working in the area of mental health or disability.

Further research and investigation into the subject of the role of consumer and family groups should be undertaken.

In conclusion, the state of mental health services in Nigeria stands to benefit from every help it can receive. Experts have opined, based on evidence from other parts of the world, that consumer groups are useful in supporting the mental health system and quite often are effective advocates to the government and the public for improvement of services, the

implementation of good policies and the making of good laws. It would be a good beginning to take lessons learnt from this active group and explore their replication and improvement to serve as a model for nation-wide application.

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APPENDIX I

QUESTIONNAIRE FOR STAFF OF DEPARTMENTS OF PSYCHIATRY/ NEUROPSYCHIATRIC HOSPITALS IN NIGERIA

Dear Sir/Madam,

Thank you for taking the time to respond to this brief questionnaire. The purpose of the questionnaire is to provide information about the existence of consumer groups and any knowledge of past efforts (if any) to establish consumer/family groups. We also seek to assess the perceived need for such groups. The information obtained will be used as part of data for a Masters Dissertation. There is no intention to mention your hospital or department by name in the dissertation.

1. Name of Hospital _____

- 2. You are a Psychiatrist-----
Social Worker-----
Psychologist-----
Nurse-----
Doctor (but not a Psychiatrist) -----

3. Do you have a group(s) consisting of mental health consumers/family members functioning within or under the auspices of your hospital?
YES NO

4. If there is no functioning group at present, please indicate if there has ever been such a group.
YES NO

5. If there was a group which no longer functions, please give any known reasons why the group stopped functioning

6. If there has never been a consumer/family group, are there plans to establish one?
YES DEFINITELY YES PROBABLY NOT LIKELY DEFINITELY NOT NOT SURE

7. Do you believe it is desirable to have consumer/family groups for mental health in your HOSPITAL?
HIGHLY DESIRABLE DESIRABLE PROBABLY NOT DEFINITELY NOT NOT SURE

8. Do you believe it is important to have consumer/family groups for mental health in your COMMUNITY? (i.e. closer to where you live)
HIGHLY IMPORTANT IMPORTANT PROBABLY NOT DEFINITELY NOT NOT SURE

9. Would you be willing to be part of an effort to start such a consumer/family group in the Community?
YES DEFINITELY YES PROBABLY NOT LIKELY DEFINITELY NOT NOT SURE

10. Where would you prefer to have your consumer/family group meetings?

Community _____

Hospital _____

Other venue (specify) _____

11. What are the areas of activity of your consumer/family group? (tick the ones that are relevant)

Supporting one another emotionally

Sharing and receiving information about mental health

Education of the public

Education of hospital staff

Advocacy to government

Advocacy to the hospital management

Bulk purchase of drugs

Establishment of community mental health facilities

Establishment of other consumer groups like yours

Participating in research

Other (specify) _____

12. Among those listed above, what 4 activities do you consider the most important?

13. What activities would you like to see the group engaged in which have not yet commenced?

14. On the whole do you think the members of your user group are satisfied with the group?

Very Satisfied-----

Satisfied-----

Dissatisfied-----

Very dissatisfied-----

15. Please add any other useful comments you may wish to further enrich this interview _____

THANK YOU FOR YOUR TIME

APPENDIX II

The Modified Stock Take & Needs Assessment of Consumer Organisations and Groups Questionnaire

Thank you for agreeing to fill in this feedback form for the as part of a Needs Assessment of your Consumer Group which is being studied for an MSc Dissertation.

This survey should take between fifteen and twenty minutes to complete.

Section A – ABOUT YOUR GROUP OR ORGANISATION AND SERVICES IT PROVIDES

This section is about the health condition or disability that is your group or organisation’s main area of focus and the services your group or organisation provides to consumers

Group’s or Organisation’s area of focus

Q1. What health condition(s) or disability(ies) does your group or organisation focus on?

Don't know.....

Q2. What is your group’s or organisation’s vision or purpose? (Please limit this to 40 words)

Don't know.....

Q3. Which of the following services has your group or organisation provided to consumers in the last 12 months?

(Please tick all that apply)

We have provided information and education to consumers

We have represented consumers’ interests or advocated on their behalf

We have provided health and disability services for consumers

We have provided awareness raising, education or training about consumers’ health condition/disability, or consumers’ needs.....

We have provided support and advice to consumers (**in general**)

Other **Specify:** _____

Don't know.....

Q4. Approximately how many consumers has your group or organisation provided these services to in the last 12 months?

(Please tick only one)

.....
Don't know.....

Q5. Does your group or organisation focus on any particular consumer groups identifiable by their ...

(Please tick all that apply)

Age.....

Gender.....

Ethnicity

*

Organisation details

Q6. In which year was your group or organisation first established?

Write in the year here: ____ ____ ____ ____

Don't know.....

Q7. Which of the following best describes your group's or organisation's current legal status?

(Please tick only one)

Charitable trust

Incorporated society

Limited liability company.....

No official legal status.....

Other **Specify:** _____.....

Don't know.....

Q8. Does your group or organisation have an National Office only, a National Office and regional offices, or regional offices only, or no offices?

(Please tick only one)

National Office **only**.....

National Office **and** regional offices

Regional offices **only**.....

A single office in a region.....

No offices (e.g. activities are managed from a private home)

Other **Specify:** _____.....

Don't know.....

Q9. Does your group or organisation have any of the following?

An elected or nominated board.....

None, we are individuals (linked by a common interest) without a formal structure.....

Other **Specify:** _____.....

Don't know.....

Q10. What number of paid staff does your group or organisation currently employ (on a part time and/or full-time basis)?

A. N. of paid full time staff.....

B. N. of part time staff (part time (work less than 20 hours per week)

C. Don't know

Q11. Does your group or organization operate with regular volunteers and/or occasional volunteers? If 'yes', about what number of regular volunteers does it currently operate with? (i.e. volunteers that participate 6 or more times each year)

No volunteer staff.....

Don't know

Section B – CONSUMER INFORMATION AND EDUCATION PROVIDED BY YOUR GROUP OR ORGANISATION

This section is about the information and education services that your group or organisation provides to consumers.

If your organisation has **provided information and education to consumers** in the last 12 months, please complete this section.

Q12. Which of the following information and education services has your group or organization provided in the last 12 months?

(Please tick all that apply)

Information and education about **how to treat/manage** the health condition or disability

Information on how to **access health or disability services**.....

Information and education on **human rights, consumer rights, inclusiveness** and related topics

Information on making **complaints or providing consumer feedback**.....

Information and education about the health condition or disability (**in general**)

Other **Specify:** _____.....

Don't know.....

Q13. Which of the following methods has your group or organisation mainly used to provide information and education services in the last 12 months?

(Please tick all that apply)

Telephone/fax.....

Email.....

Website.....

Face-to-face.....

Print media (newsletters, magazines, advertising)

Via third parties (e.g. GPs other treatment providers, Citizens Advice Bureau, etc.)

Other **Specify:** _____.....

Don't know.....

If you had ticked “website” at Q13, please answer the following question.

Q14. For which of the following reasons has your group or organisation used web-based communications?

(Please tick all that apply)

To respond to ad hoc enquiries

To provide advice, information or updates on progress relating to current issues

To provide specific information, research and education pages.....

Other **Specify:** _____.....

Don't know.....

If you had ticked “website” at Q13, please answer the following question.

Q15. And which of the following web-based tools has your group or organisation used to provide these services?

(Please tick all that apply)

Social networking such as Blog, FaceBook, Bebo, WhatsApp, etc.....

Messaging such as Twitter

On-line newsletters or updates

E-communities such as Wiki.....

Other **Specify:** _____.....

Don't know.....

Q16. Which of the following methods do you think your group or organisation has found the most effective in providing information and education services in the last 12 months?

(Please tick all that apply)

- Telephone/fax.
- Email.....
- Website.....
- Face-to-face.....
- Print media (newsletters, magazines, advertising)
- Via third parties (e.g. GPs other treatment providers, Citizens Advice Bureau, etc.).....
- Other **Specify:** _____.....
- All equally effective
- Don't know.....

If you had ticked “face-to-face” at Q13, please answer the following question. Q17. For which of the following reasons has your group or organisation used face-to-face communications?

(Please tick all that apply)

- To respond to ad hoc enquiries from consumers who visit an office.
.....
- To visit consumers in their homes
- To attend and/or make contributions at support meetings.....
- To attend and/or make presentations at consumer groups, expos of other similar gatherings.....
- To attend and/or make presentations at conferences/seminars....
- Other **Specify:** _____.....
- Don't know.....

Q18. For which of the following types of information and education has your group or organisation used paid consultants in the last 12 months? By paid consultants we mean external parties who are paid fees for their services and expertise.

(Tick all that apply)

- | | | | | |
|--------------------|--------------------|-------------------------|-----------------|----------------------------|
| | <i>General</i> | <i>How to
treat</i> | <i>how to</i> | <i>consumer/
human</i> |
| <i>making</i> | | | | |
| <i>complaints/</i> | <i>Information</i> | <i>manage the</i> | <i>access</i> | <i>rights</i> |
| | | <i>Condition</i> | <i>services</i> | <i>feedback</i> |

Q19. What is/has been the greatest assistance to your group or organisation in terms of your ability to provide information and education services to consumers?

Nothing/No one has been the greatest asset

Don't know.....

Q20. For which of the following types of information and education services does your group or organization plan to invest in, in order to build its capacity, over the next 12 months?

	General	How to	how to	consumer/	making
information	manage the	treat/	rights	human	
condition	services	access	feedback	complaints/	
		information			

Q21. What is/are the greatest barriers facing your group or organisation in terms of the provision of information and education services to consumers in general?

My group or organisation has no barriers.....

Don't know.....

Section C – CONSUMER REPRESENTATION AND ADVOCACY PROVIDED BY YOUR ORGANISATION

This section is about the representation and advocacy services that your group or organisation has provided to consumers.

If your organisation has **represented consumers' interests or advocated on their behalf** in the last 12 months, please complete this section. Otherwise, go to Q31.

Q22. What issues has your group or organisation advocated on for consumers in the last 12 months?

(Please tick all that apply)

Access to health and disability services and treatments
(e.g. access to specialised services or treatments)

Quality of health and disability services.....

Cost of health and disability services (e.g. cost of expensive or new medicines)

Other **Specify:** _____

Don't know.....

Q23. And which of these issues, including any other (emerging) issues is your group or organisation likely to be advocating on in the next 12 months?

(Please tick all that apply)

Access to health and disability services and treatments
(e.g. access to specialised services or treatments)

Quality of health and disability services.....

Cost of health and disability services (e.g. cost of expensive or new medicines)
.....

Will **not** advocate any issues in the next 12 months

Other **Specify:** _____

Don't know.....

Q24. To which of the following has your group or organisation advocated to in the last 12 months?

(Please tick all that apply)

Members of National Assembly.....

Government officials (e.g. the Ministry of Health, Pharma, Wages Commission).....

Local government Chairmen& elected counsellors.....

Local government officials.....

Hospital Boards.....

Professional bodies (e.g. Postgraduate medical Colleges)

Other **Specify:** _____

Q25. Which of the following methods has your group or organisation used to advocate in the last 12 months?

(Please tick all that apply)

Direct advocacy and negotiation

Providing representatives on national or regional committees.....

Preparing and submitting/presenting submissions

Media presence (e.g. radio shows, radio talkback, newspaper/magazine articles)

Other **Specify:** _____

Don't know.....

Q26. Who has carried out this advocacy activity on behalf of your group or organisation in the last 12 months?

(Please tick all that apply)

Designated paid staff, responsible for consumer representation or advocacy

Other paid staff

Voluntary staff.....

Whoever knows best about the issue

Whoever has the time.....

Paid consultants

Other **Specify:** _____

Don't know.....

Q27. Does your group or organisation do any of the following to gather consumers' views in order to advocate on behalf of consumers.

(Please tick all that apply)

Systematically collect feedback from staff and volunteers who have direct contact with consumers.....

Make ad hoc requests to staff and volunteers.....

Conduct consumer surveys

Make ad hoc requests to consumers

Conduct consumer meetings or workshops on issues

Have comments or suggestion boxes in health services, Clinics or via your group's or organisation's website

Other **Specify:**

Do not gather consumers' views.....

Don't know.....

Q28. Does your group or organisation have or do any of the following to enable its advocacy activities?

(Please tick all that apply)

Has advocacy guidelines

Produces factsheets on key issues (e.g. summary of evidence/data and your stance).....

Has a consumer advocacy network, group or committee.....

Completes advocacy training with staff and/or volunteers.....

Other **Specify:**

Don't know.....

Q29. What is/has been the greatest assistance to your group or organisation in terms of conducting advocacy activities in general?

Nothing/No one has been the greatest assistance

Don't know.....

Q30. What is/are the greatest barriers facing your group or organisation in terms of conducting advocacy activities in general?

My group or organisation has no barriers.....
Don't know.....

Section D – FUTURE ACTIVITIES

This section is about the activities that your group or organisation plans to undertake in the next 24 months.

Supporting consumers

Q31. If your group or organisation was to better support your consumers in this goal?

Please tick only one option for each attribute A - F. If you are unsure about the aspect, please select “don't know”

- 1. Not at all important**
- 2. Of little importance**
- 3. Moderately important**
- 4. Important**
- 5. Very important**

- A. Support and advice to consumers.....
- B. Information and education services to consumers.....
- C. Representation and advocacy on behalf of consumers.....
.....
- D. Organisational structure and Governance
- E. Staff education and training
- F. Funding.....

If you have ticked code 4 or 5 for “information and education” at Q31, please answer the following question. Otherwise, please go to Q34.

Q32. In terms of information and education services, which of the following activities would your group or organisation most likely focus on for the greatest impact?

(Please tick all that apply)

- Conducting research to develop information and education services.....
- Developing new ways/channels for providing web-based information and education (website, social media)
- Developing and publishing new materials (booklets, fact sheets) ..
- Developing new education or information services..... ..
- Conducting research or review of information and education services

All activities

Other **Specify:** _____

Don't know.....

If don't know **Go to Question Q34**

Q33. What are the main barriers to your group or organisation doing these activities?

No barriers.....

Don't know.....

If you have ticked code 4 or 5 for “representation and advocacy” at Q31, please answer the following question. Otherwise, please go to Q36.

Q34. In terms of representation and advocacy, which of the following activities would your group or organisation most likely focus on for the greatest impact? (Please tick all that apply)

Developing new relationships with government agencies, Hospital management Boards and others.....

Increasing the level of representation on decision-making committees and groups within government agencies (including DHBs), local government and professional bodies.....

Conducting research or review of representation and advocacy activities.....

All activities.....

Other **Specify:** _____

Don't know.....

If don't know **Go to Question Q36**

Q35. What are the main barriers to your group or organisation doing these activities?

No barriers.....

Don't know.....

Organisational structure and governance

If you have ticked code 4 or 5 for “organisational structure and governance” at Q31, please answer the following question. Otherwise, please go to Q38.

Q36. In terms of organisational structure and governance, which of the following activities would your group or organisation most likely focus on for the greatest impact?

(Please tick all that apply)

Review or change group’s or organisation’s governance

Complete a strategic review or strategic planning

Review quality/outcomes of group’s or organisation’s role in supporting, educating or advocating for consumers.....

Review funding, resourcing and/or staffing levels.....

Prepare a new financial or business plan.....

Develop new funding partnerships, or access major new funding or grants.....

Develop new relationships with government agencies, Hospital Management Boards and others (to enhance your consumer representation and advocacy activities).....

Extend group’s or organisation’s advocacy activities

All activities

Other **Specify:** _____

Don’t know.....

If don’t know Go to Question Q38

Q37. What are the main barriers to your group or organisation doing these activities?

No barriers.....

Don’t know.....

If you had ticked code 4 or 5 for “staff education and training” at Q31, please answer the following question. Otherwise, please go to Q40.

Q38. In terms of staff education and training, which of the following activities would your group or organisation most likely focus on for the greatest impact?

(Please tick all that apply)

Education of volunteers or staff (for providing education and information to consumers and others).....

Education/Training of volunteers or staff (for providing support and advice to consumers)

Education/Training of volunteers or staff (for advocacy)

Education/Training of volunteers or staff (for governance or organisational management roles)

All activities

Other **Specify:** _____

Don't know.....

If don't know Go to Question Q40

Q39. What are the main barriers to your group or organisation doing these activities?

No barriers.....

Don't know.....

If you had ticked code 4 or 5 for "funding" at Q31, please answer the following question.

Otherwise, please go to Q42.

Q40. In terms of funding, which of the following activities would your group or organization most likely focus on for the greatest impact?

(Please tick all that apply)

Reviewing funding, resourcing and/or staffing levels

Developing funding partnerships, or accessing new funding or Grants.....

All activities

Other **Specify:** _____

Don't know.....

If don't know Go to Question Q42

Q41. What are the main barriers to your group or organisation doing these activities?

No barriers.....

APPENDIX 3

QUESTIONNAIRE FOR SERVICE USERS OF DEPARTMENTS OF PSYCHIATRY/ NEUROPSYCHIATRIC HOSPITALS IN NIGERIA

Dear Sir/Madam,

Thank you for taking the time to respond to this brief questionnaire. The purpose of the questionnaire is to provide information about the existence of consumer groups and any knowledge of past efforts (if any) to establish consumer/family groups. We also seek to assess the perceived need for such groups. The information obtained will be used as part of data for a Masters Dissertation. There is no intention to mention your hospital or department by name in the dissertation.

Would you like to participate? Yes No

(If no, stop the survey here and thank the person for his or her time.)

Name of Hospital _____

Respondent ID NO _____

1. Name: **PLEASE DO NOT WRITE DOWN THE RESPONDENTS NAME**

2. Age (In years):

3. Sex: Male Female

4. Marital Status:

Single

Married/cohabiting

Divorced/separated

5. Education: Years of schooling _____

6. Occupation:

Skilled (Specify _____)

Unskilled (Specify _____)

7. Category of service user:

Self

Family member/carer

8. How did you learn about the existence of this group?

In Clinic/on the ward as part of health talk

Personal approach by a staff member

Through a friend

Flyers/Handouts

Text message

Other (specify) _____

1. How long have you been a member of this consumer/family group?

Less than one year

Number of years _____

9. About how many times have you been to this support group in the last year?

___ 0 ___ 1 ___ 2 – 5 ___ 6 – 10 ___ more than 10

10. Do you believe it is beneficial to belong to this consumer/family groups for mental health?

___ HIGHLY BENEFICIAL

___ BENEFICIAL

___ PROBABLY NOT

___ DEFINITELY NOT

___ NOT SURE

11. People attend support groups for different reasons. The following list describes different reasons why you may have come to this support group. Every person wants and needs different things, so there are no “right” answers.

12. Please use one of the numbers in the box below to rate each of the items on the list according to the help you received from the support group:

___ Talking to others who understand my situation

___ Information about counseling options

___ Learning more about why/how mental illness happens

___ Support to make some changes in my life/my relative’s life

___ Understanding myself/my relative better

___ Feeling better about myself

___ Finding out where to get help

___ Feeling more hopeful about my life

___ Other (describe)

13. I am most comfortable talking about my issues and concerns related to the issues I have experienced in the following way (please check only one):

___ In a support group with other users who have had similar experiences

___ In a conversation with only one other person

___ I am equally comfortable talking in a group or with just one person

14. Which if any of the following have you benefitted from?

___ Financial support

___ Obtaining cheaper drugs

___ Obtaining useful health information

___ Social support/Social Network

___ Making new friends

___ A place to talk freely about our health concerns

___ Others (specify) _____

15. Do you have any regrets/reservations about belonging to this group?

___ No
___ Yes (specify) _____

16. Do you believe it is desirable to have consumer/family group for mental health in your community (i.e. closer to where you live)?

HIGHLY IMPORTANT IMPORTANT PROBABLY NOT DEFINITELY NOT NOT SURE

17. Where would you prefer to have your consumer/family group meetings?

Community

Hospital

Other venue (specify)

18. What are the areas of activity of your consumer/family group? (tick the ones that are relevant)

Supporting one another emotionally

Sharing and receiving information about mental health

Education of the public

Education of hospital staff

Advocacy to government

Advocacy to the hospital management

Bulk purchase of drugs

Establishment of community mental health facilities

Establishment of other consumer groups like yours

Participating in research

Other (specify) _____

19. Among those listed above, what 4 activities do you consider the most important?

20 What activities would you like to see the group engaged in which have not yet commenced?

IWE IBERE FUN AWON ENI TI O NLO ILE IWOSAN FUN AILERA OPOLO ATI AWON TIO SISE
AILERA OPOLO TABI OKAN ORILE EDE NAIJIRIA

ARA WA OWON

Ese fun akoko te e fun wa lati dahunsi awon ibeere ni soki yii. Idi Pataki ti a fi gbe awon ibeere yi kale ni lati pese awon alaye lori igbekale awon egbe yii ati awon imo lori awon akitiyan ti o koja. (be eyikeyi) lati se agbekale awon egbe tabi awon idile. A si n wo ona ti a le fi dasi ohun ti awon egbe yi nilo. Awon oro ti aba gba sile ni a o lo fun ise iwadi awon akekogboye eleেকেجي ni ile eiwe giga fasiti. A ko ni ero lati daruko ile iwosan yin tabi eka ti e wa ninu eto iwadi naa.

Se o wu yin lati kopa? _____ Beeni _____ Beeko

(If no, stop the survey here and thank the person for his or her time.)

Oruko Ile iwosan _____

Nomba idanimo olukopa _____

1. Oruko yin: E JOWO E MA SE KO ORUKO YIN S'ILE

2. Ojo ori (ni odun):

3. Okunrin _____ Obinrin _____

4. Ipo loko/laya:

_____ Apon

_____ Lokolaya/gbepo bi lokolaya

_____ Kosile/Pinya

5. : Iwe melo ni e ka _____

6. Ise wo ni e nse?:

_____ Akosemose (e so nipato) _____)

_____ E ko ko ise (e so nipato) _____)

7. Iru awon ti o nlo ile iwosan:

_____ eyin gan

_____ ebi/eni ti e ntoju

8. Bawo ni e se gbo nipa egbe yi?

_____ Ni ile iwosan/Woodu nigba ti won dani leko oro ilera

_____ Osise kan wa ba emi gangan so oro

_____ Ore lo so fun mi

_____ Iwe pelebe tabi iwe ilewo ti won npin

___ Atejise
Omiran (e so nipato) _____

9. Ato igba wo leti dara po mo egbe yi?

Kere si odun kan
Eso iye odun _____

_10. Ato bi e melo ni e wa si ipade egbe nikan bi odun kan s'ehin ?
___ 0 ___ 1 ___ 2 – 5 ___ 6 – 10 ___ more than 10

11. Nje e ni igbagbo wipe o se yin lanfaani lati darapo mo egbe yi?

___ O se anfaani lopo lopo
___ O se anfaani
___ O se anfaani die
___ Ko se anfaani
___ Ko daju

12.. Awon enia ma ndarapo mo iru egbe yi fun idi kan tabi omiran. Awon akosile to wan i isale yi je apere iru idi wonyi. Gege bi asemo wipe oun to wumi kowu o, kosi idahun ti ko tona. Jowo lo eyi keyi ninu awon nomba ti o wa ni isale yi lati se odiwon awon ohun ti ako si sale yi gege bi iranlowo ti e ngba lati inu egbe yi.

1. O se patakii lopo lopo
2. O se patakii
3. O se patakii die
4. Ko se pataki rara
5. Ko daju.

___ Bi ba awon eni ti oro mi ye soro
___ Mo gbo nipa orisirisi ibi ti won ti le gba mi ni iyanju
___ Nini imo si nipa idi ati bawo ni aisan opolo se nsele
___ Mo nri aduroti ti o mu iyato deba igbesi aiye mi tabi ti molebi mi
___ Oro ara mi tabi ti ebi mi nye mi si
___ Inu mi ma dun nipa ara mi si
___ Mimo nipa ibi ti mo ti le ri iranlowo gba
___ Mo ni ireti ti o po si nipa igbesi aiye mi
___ Omiran (e juwe)

13. O te mi l'orun lati so oro oro mi/oro enia mi ati awo ti o je mi l'ogun ni ona yi (e mu okan): ___ ni arin egbe agbateru pelu awon omiran ti o ti ni iriri bi t'emi

___ Ti mo ba ba eni kan soso s'oro

___ Bakan na ni fun mi ti mo ba soro ni arin egbe tabi ti mo ba ba enikan soso soro

14. Ewo ninu awon eleyi ni eti je anfani e?

___ Iranlowo owo

___ Gbigba oogun olowo pooku

___ Gbigba oro ilera to seni lanfani

___ Iranlowo egbe tabi egbe atakanle

___ Nini ore tuntun

___ Aye lati soro nipa ilera wa tokantokan

___ Omiran(e so nipato) _____

15. Se eni awon abamo tabi oro senihun nipa didarapo mo egbe yi

___ Rara

___ Beeni (e so nipato) _____

16. Se e ni gbagbo wipe o dara lati ni egbe fun ailera opolo ni adugbo yin.(sisumo ibi ti e ngbe)?

1. O se patakii lopo lopo

2. O se patakii

3. O se patakii die

4. Ko se pataki rara

5. Ko daju.

17.Nibo ni o ma wu yin lati ma se ipade egbe

Adugbo

Ile iwosan

Ibi miran (e so nipato)

18.Orisirisi ise ti egbe yin se? (e mu ikan ti o ba mu)

Diduroti ara eni ninu nigba isoro

Sise asaro tabi gbigba oro nipa ailera opolo

Idanileko ita gbangba

Idanileko fun osise ile iwosan

Alagbawi fun ijoba

Alagbawi fun isakoso ile iwosan

Rira ogun loju paali

Dida ile iwosan ailera opolo lagbegbe sile

Dida egbe miran bi eyi sile

Kikopa ninu eto iwadi

Omiran (e so nipato) _____

.

19. Lara awon ti a so soke yi, daruko awon ise merin ti e ro pe ose pataki julo

20 Awon ise wo ni a wu yin lati ri ki egbe yi ma se ti ko won ko ti ma se.
