SCHOOL OF PUBLIC HEALTH

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EXPERIENCES OF STIGMA AGAINST PERSONS WITH SCHIZOPHRENIA IN THE OKAIKOI SOUTH DISTRICT

BY

JESSICA OWOO

(10602613)

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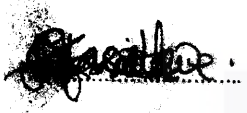
JULY, 2017

DECLARATION

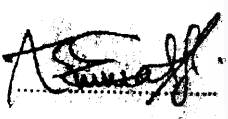
I, Jessica Owoo, declare that this study on the Experiences of stigma against persons with schizophrenia in the Obuasi South District is a true reflection of my own independent work. I further declare that this research work or part thereof has not been submitted for a degree in any other institution of higher education.



Date 13th Oct 2017

Jessica Owoo

(Student)



Date 16/10/2017

Dr. Emmanuel Asampong

(Supervisor)

DEDICATION

This work is dedicated to my dear uncle Isaac Bampoe-Addo for his unending love and contribution in my life. I am so grateful to him for how far I have come. I love you.

ACKNOWLEDGEMENTS

First of all, I wish to express my profound gratitude to the Almighty God for keeping me throughout this moment in my life. This work could not have been possible without the help and contributions of other individuals. I am highly indebted to my supervisor, Dr. Emmanuel Asampong for his support and guidance offered me in making this work a success. My sincere thanks goes to Philip Tabong, Virtue De-Gaulle, Joyce Ndekugri, Renee Abbey and every individual who has in one way or the other assisted me in bringing this work to fruition. I am most grateful to Kaneshie Polyclinic for their immense support and advice which got me here. Finally, I acknowledge all the Faculty members of Social and Behavioral Sciences and School of Public Health for the time and encouragement given me throughout my stay in the university.

ABSTRACT

Background: Mental illnesses attract a lot of stigma. However schizophrenia is one of the most stigmatized mental conditions because of its perceived dangerousness and unpredictability. The stigma experienced by persons with schizophrenia can hinder help-seeking behaviours further exacerbating their condition. It is therefore important to find out the experiences of stigma among the family and persons with schizophrenia in order to come up with intervention to stop such behaviours in public. This study sought to explore experiences of stigma against family, caregivers and persons with schizophrenia.

Methods: This study employed a qualitative research approach using two focus group discussions (N=18) among schizophrenic patient and eight (8) in-depth patients (3 among patients and 5 among patients relatives). Purposive sampling technique was used to select the study participants. All interviews were recorded and transcribed verbatim after which manual thematic content analysis was used to generate themes. Various themes on perceived causes of schizophrenia and experiences of stigma among the study population were explored.

Result: The study revealed that schizophrenia is caused by supernatural forces. *It* was the view of participants that, people get schizophrenia because of curses, evil machinations and demonic attacks and such people are afraid of people who have the condition and their family members. The study further revealed that people with schizophrenia and their relatives are stigmatised at the community. Due to these stigmatizing attitude, family members and persons with schizophrenia avoided social gatherings like funerals, wedding and naming ceremonies. The family members also revealed the burden they suffer due to the caregiving role.

Conclusion: Schizophrenia is believed to be spiritual mental health condition and stigmatization of patients with schizophrenia and their relatives was common in the community. As a result of the stigma both patients and relative stay away from public gathering and resort to spiritual healers for health care.

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CHAPTER ONE

INTRODUCTION

1.1Background

Mental and behavioral health issues are believed to contribute to about 12 percent of the global burden of disease and is projected to increase to 15 percent by the year 2020, (WHO, 2001). Schizophrenia is named as one of the most severe mental illnesses in the world (Whiteford *et al.*, 2013). The disease affects a person's ability to think clearly, control emotions, make decisions and relate to others (Frith, 2014). Furthermore, it impairs a person's ability to function to their potential when left untreated (Frith, 2014). Schizophrenia usually starts in the teenage years or early adulthood and it is usually a chronic and disabling condition (Fujino & Okamura, 2009). The exact cause of schizophrenia is still unidentified; however, researchers have recognized that the brains of people living with schizophrenia are different from those undiagnosed with the illness (Horrobin, Manku, Hillman, Iain, & Glen, 1991). The development of schizophrenia has been attributed to both genetic and environmental factors (Tsuang, 2000; Van Os, Kenis, & Rutten, 2010). Although there is no cure for the disease, there are effective treatments which can enable affected people live productive lives and be integrated into the society (Miyamoto, Duncan, Marx, & Lieberman, 2005).

The World Health Organization (WHO), (2001) estimates that nearly 21 million people worldwide are schizophrenics. Its incidence is about 3 per 10,000 people yet, its prevalence is high due to the chronic nature of the illness (WHO, 2001). The only published population based epidemiological study on the prevalence of schizophrenia in Ghana was conducted in 1984 and it was estimated to be about 2 per 1000 persons (Sikanartey & Eaton, 1984). Based on this

prevalence, the WHO epidemiological formula for the estimation of psychiatric problems in any given population was employed in the estimation of people with mental health problems in Ghana. Thus, it was estimated that approximately 240,000 people suffer from severe mental disorders and 2,400,000 suffer from some form of mental disorder in Ghana (Doku, Wusu-Takyi, Awakame, & others, 2012)

Persons with schizophrenia do not battle with the symptoms of the illness only (Schulze & Angermeyer, 2003) but are faced with stigma. Ervin Goffman describes stigma as a phenomenon whereby a person with a particular trait is intensely discredited by his or her society as a result of the trait (Goffman, 1963). Although generally mental illnesses are stigmatized, schizophrenia appears to be the most stigmatized disorder (Lee, Lee, Chiu, & Kleinman, 2005). Schizophrenic patients experience stigma from family members, friends, partners and work colleagues (Lee, Lee, Chiu, & Kleinman, 2005). These persons are marginalized either from community life, in housing, education, employment and family relationships (González-Torres, Oraa, Arístegui, Fernández-Rivas, & Guimon, 2007). Stigma and discrimination of persons with schizophrenia can result in a lack of access to health and social services because affected persons do not want to be identified (Corrigan, 2004).

Caregivers are the main support system of care for individuals with schizophrenia at home (W.H.O, 2001). But, caregivers such as the family and health care givers also have their fair share of the stigma of the illness (Östman & Kjellin, 2002). The stigma and discrimination experienced by family members especially caregivers of patients with schizophrenia are usually in the form of rejection, blame and avoidance by others. This begets hurt, disappointment and

shame (Karnieli-Miller *et al.*, 2013; Muhlbauer, 2002). There is a need to ascertain reasons for the stigma of schizophrenic persons and their caregivers and educate the perpetrators to stop.

1.2 Statement of the problem

Approximately 240,000 people suffer from severe mental disorders and 2,400,000 suffer from some form of mental disorder in Ghana (Doku, Wusu-Takyi, Awakame *et al.*, 2012). By June, half year of 2016, a total of 131 clients with mental illness were registered in the Okai Koi South Sub Metro. Unfortunately mental health is highly stigmatized and persons suffering from schizophrenia are the most stigmatized. The family and care givers of schizophrenic persons also experience courtesy stigma as Goffman (1963) puts it. He explains it as stigmatization by virtue ones association with a stigmatized person. Many people with schizophrenia who would benefit from mental health services sometimes decide not to utilize them or fail to fully participate once they have begun for fear of being stigmatized. Stigma yields two kinds of harm; impede treatment participation and diminishes self-esteem which robs people of social opportunities. Family members who experience stigma by virtue of their association with schizophrenic person conceal the existence of the disease in an affected person thus not seeking care for the person or withdrawing from care or to avoid the stigma. In effect, schizophrenic persons who could be treated and given the opportunity to live productively are deprived of it. There is a need to find out the experiences of stigma encountered by schizophrenic persons and family in Ghana in order to develop educative interventions.

1.3 Justification

Schizophrenia is one of the most severe mental illnesses in the world (Whiteford *et al.*, 2013). It obstructs a person's ability to think clearly, manage emotions and relate to others (Frith, 2014). It usually includes psychotic experiences, such as hearing voices or delusions (W.H.O, 2001). Stigma of schizophrenia leads to discrimination and this prevents people from seeking health care, accessing education, housing and sometimes employment (WHO, 2001). It will therefore be of great importance to find out the experiences of stigma among schizophrenic persons and their family. Findings from this study will provide information on experiences of stigma, causes and how schizophrenic persons and family cope with the stigma experienced. Furthermore, it can inform the design of effective educational interventions that seeks to address the problem of stigmatization of schizophrenia among Ghanaians. Recommendations from this study may be useful in informing policy makers on factors to consider when developing policies in relation to stigma of mental health illnesses in Ghana.

1.4 Study Objectives

1.4.1 General objective

- To explore experiences of stigma among family, caregivers and persons with schizophrenia.

1.4.2 Specific objectives

- To investigate schizophrenic persons experiences of stigma.
- To explore experiences of stigma among family members of schizophrenic persons

1.5 Research questions

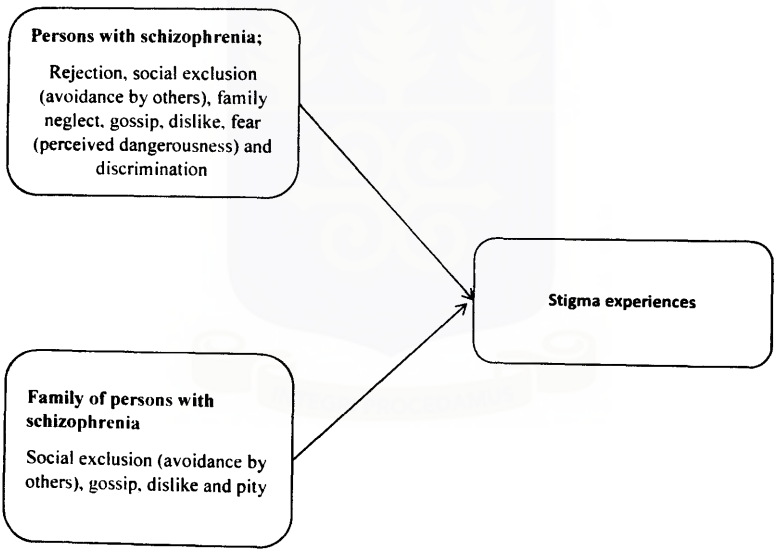
- What are the experiences of stigma encountered by persons with schizophrenia?
- What are the experiences of stigma encountered by family members of schizophrenic persons?

1.6 Conceptual framework

The conceptual framework of this study is based on Ervin Goffman's (1963) description of social stigma which he defines as "the process by which the reaction of others spoils normal identity." In Erving Goffman's theory of social stigma, a stigma is an attribute, behavior, or reputation which is socially discrediting in a particular way: it causes an individual to be mentally classified by others in an undesirable, rejected stereotype rather than in an accepted, normal one. Goffman explains that society establishes a means of categorizing people based on their attributes, each person is categorized based on his or her attribute which is termed the social identity. When a person possesses an attribute that makes him different, less desireble from others in the category of persons in a particular society or community, that person is seen as bad, or dangerous, or weak. The person is thus reduced from a whole and usual person to a tainted, discounted one, such an attribute is a stigma, especially when its discrediting effect is very extensive.

Goffman goes on to elaborate on three forms of social stigma, one of which pertains to mental illness or the burden of such diagnosis. The stigmatized who in this instance will be a mentally ill person is ostracized, devalued, rejected, scorned and shunned. The mentally ill person may also experience discrimination or insults. Goffman (1963) further goes on to explain stigma by association where persons associated with stigmatized persons are subjected to stigmatizing attitudes like being shunned or pitied.

Using Goffman's description of social stigma which emphasizes deviations in personal traits, such as observed mental health disorders like Schizophrenia, the researcher designed a framework which conceptualizes that persons with schizophrenia may experience rejection, family neglect, social exclusion, gossip, dislike and discriminated against because of their condition. Similarly, using courtesy stigma by Goffman (1963), which is stigma experienced by virtue of ones association with the stigmatised individual, their family members who are associated with schizophrenic persons may also experience stigma through social exclusion (avoidance by others), gossip and pity.



(Source: Authors design)

Figure 1: Conceptual framework on experiences of stigma among family and persons with schizophrenia

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

This chapter reviews literature using the objectives and the problem statement as a guide. The focal points of the review are mental health, schizophrenia, causes and risk factors, prevalence of schizophrenia, stigma of schizophrenia and other mental health conditions, stigma of caregivers of mental health persons.

2.2 Mental health

The World Health Organization defines mental health as a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community (WHO, 2013). Sound mental health and well-being are central to our communal and individual ability as human beings (Allen, Balfour *et al.*, 2014). Therefore, it is important that good mental health be promoted as well as protected among everybody in the world thus its inclusion in the sustainable development goal. Mental disorders are responsible for 160 million lost years of youthful life, of which about 30% could be prevented with available interventions (WHO, 2012). There are numerous forms of mental illnesses but generally there are five categories of mental illnesses and they are anxiety disorders, mood disorders, schizophrenia or psychotic disorders, dementia and eating disorders (APA, 2016). Anxiety disorders which can manifest in the form of phobias, agoraphobia, social anxiety disorder or panic differs from normal feelings of nervousness or anxiousness but rather involves extreme panic or anxiety (Barlow 2004). Anxiety disorders are the commonest of mental disorders and affect most adults at some point in their lives (Barlow 2004). However anxiety disorders can be treated with medications and psychotherapy which

will enable affected persons to lead normal productive lives (Cuijpers, Marks *et al.*, 2009, Ravindran and Stein 2010). Mood disorders, another form of mental illness encompass depression, bipolar disorder, and cyclothymic disorder (Tsuang & Faraone, 1990). These disorders, also termed affective disorders and they include continuous feelings of unhappiness or periods of euphoria or changes from extreme happiness to extreme sadness (Tsuang & Faraone, 1990). Eating disorders include extreme sentiments, attitudes, and behaviours concerning weight and food (Fairburn & Harrison, 2003). With conditions such as anorexia nervosa, bulimia nervosa, and binge eating disorder being the commonest of the eating disorders (Fairburn & Harrison 2003). Mental health conditions or disorders can be caused by different social, economic, and physical environments working at different phases of life. For example Murali & Oyebode, (2004) explain how poverty and social inequality influence mental health behaviours and conditions such as alcohol and substance abuse, suicide and psychosis. Mental conditions like psychosis can be caused by too little sleep, brain tumours, some medications, substance abuse and distressing events, like the death of a loved one or a sexual assault (Coren 1998; Morrison, Frame *et al.*, 2003; Goerke & Kumra 2013).

2.2 Schizophrenia causes and risk factor

Schizophrenia is a chronic life altering condition that is characterized by distortions of thinking and perception, disorganized behaviour, hallucinations and delusions (Snyder, Kety, & Goldstein, 1982). The illness was first described by Emil Kraepelin in 1896, who named it Dementia Praecox or premature dementia because he believed that the condition always had an increasingly deteriorating course and even any improvement over time it would only be partial (Kraepelin, 1987). Eugen Bleuler renamed Kraepelin's Dementia Praecox as schizophrenia in 1911 as he identified it as cognitive impairment which he termed "splitting" of mind (Bleuler,

1911). Later, Kurt Schneider emphasized the role of psychotic symptoms, such as hallucinations and delusions as being characteristic of schizophrenia (Schneider, 1957). Schizophrenia has been associated with a number of probable causes among which aspects of brain chemistry and structure, as well as environmental causes (Snyder, Kety, & Goldstein, 1982).

Clinical presentation of schizophrenia differs generally among affected individuals and even within the same individual at different stages of the illness, however some of the following symptoms are common to most schizophrenic persons and these include thought disorder, delusions, hallucinations, abnormal affect, and disturbances in motor behavior (Frith, Blakemore et al., 2000, Lehman, Lieberman et al., 2004). Other manifestations such as thought, language and communication disorder which can usually be seen from irregularities in spoken or written languages with examples like continuous deviation in speech, poor speech content is not just present in schizophrenic persons but also their first-degree relatives (Levy, Coleman et al., 2010). Furthermore, several studies have documented hallucinations which involves perceptions in the absence of external stimuli as well as auditory verbal hallucinations especially voices and bizarre physical sensations as a common symptom among schizophrenic persons (Kühn and Gallinat 2010, Vercammen, Knegtering et al., 2010, Ćurčić-Blake, Nanetti et al., 2015). Disturbances in motor behavior such as maintaining odd or weird positions for prolonged times, aimless movement patterns or reduction of spontaneous movements with an apparent lack of awareness of surroundings are also symptoms exhibited by schizophrenic persons (Walther & Strik 2012). Although the precise cause of schizophrenia isn't known, certain factors seem to increase the risk of developing or triggering the disorder. These include a family history of the disorder, increased immune system activation, older age of the father, some pregnancy and birth complications, such as malnutrition or exposure to toxins or viruses that may impact brain

development (Brown, 2006; Hawton, Sutton, Haw, Sinclair, & Deeks, 2005; Neves-Pereira et al., , 2005). Persons with Schizophrenia are perceived to be dangerous and violent, however, Walsh, Buchanan et al., (2002) report that most people with schizophrenia are not violent, they are more likely to harm themselves than others, however, abusing substances can make them violent. This was corroborated by a systematic review conducted by Gulati et al., (2009) who found that although schizophrenia and other psychotic conditions are perceived to be violent towards other people that are not the case, rather their violence against other people is catalyzed by substance abuse comorbidity.

2.3 Prevalence of schizophrenia

Schizophrenia is seen as one of the most severe forms of mental illness with a worldwide prevalence of 1.4 to 4.6 per 1000 people (Jablensky, 2000). The disorder affects about 21 million people worldwide (WHO, 2001). Schizophrenia is reported to occur 1.4 times more frequently in males than females globally (Aleman, Kahn, & Selten, 2003). The World Health Organization reported the age-standardized prevalence of schizophrenia to be 343 per 100,000 in Africa (Ayuso-Mateos, 2014). The prevalence of the disorder was however estimated to be 2 per 1000 people in a population-based epidemiological study conducted as far back as 1984 in Ghana (Sikanartey & Eaton, 1984). Based on this prevalence rates, approximately 240,000 people have been estimated to suffer from severe mental disorders and 2,400,000 suffering from some form of mental disorder in Ghana (Doku, Wusu-Takyi, Awakame, & others, 2012). Although, generally the rate of newly diagnosed cases of schizophrenia is low, its early inception, long duration, and severe disability make it one of the primary contributors to the burden of disease in less developed countries (Aleman, Kahn, & Selten, 2003).

2.4 Stigma mental illnesses

One cannot talk about stigma without making reference to Erving Goffman's ground-breaking work on the subject. Goffman (1963) described stigma as an attribute that is deeply discrediting. He described how possessing a stigmatizing trait basically imposes on how others perceive the individual. Jones, Farina, Hastorf, Markus, Miller, and Scott, (1984) revised Goffman's definition of stigma and called it a "mark" or a "deviation from a norm" that links the bearer to undesirable attributes that discredit him or her in the eyes of others (Jones, Farina *et al.*, 1984). A number of researches on mental illness and how it relates to stigma have been conducted (Weiss, Ramakrishna & Somma, 2006; Major & O'Brien, 2005). Stigma adds up to the WHO fact sheet recognized as the hidden burden of mental illness (WH O, 2008), and it presents a hidden liability for other stigmatized conditions as well. It has also been shown that stigma and labeling may affect the course of recovery (Link *et al.*, 1997). The negative opinions and stigma attached to the different mental disorders vary, for example, persons with schizophrenia and bipolar disorder are perceived more negatively than people with anxiety and depressive disorders (Griffiths *et al.*, , 2006). This is probably due to the traits or characteristics relating to dangerousness and or unpredictability (Griffiths *et al.*, 2006). Research shows that public attitudes toward mental illness are generally negative and have detrimental effects on the lives of individuals who are affected (Corrigan, 2004; Link, Struening, Neese-Todd, Asmussen, & Phelan, 2001). Unfair treatments meted out to people who have suffered from mental disorders makes it impossible to live in the society after they have been discharged. Experiences of stigma associated with mental illness can be life threatening to the patients (Schulze and Anger, 2003). Stigma and unequal treatment inhibits patients with mental illness from assessing the fundamental family and civic care that everyone is eligible to enjoy (Carne, 1998). They obstruct

social blend, gets in the way of performing their basic social roles that reduces their value of living and prevent timely access to effective healthcare making a vicious round of communal difficulties and incapacities (Stolzman, 1994). Corrigan and Watson (2002) suggested that the central part of the mental illness stereotype is the perception of dangerousness and unpredictability. Stereotypes are difficult to eradicate and can endure for years (Corrigan and Watson (2002). Therefore, the negative effects of the label of mental illness can continue even after recovery (Millward, Lutte, & Purvis, 2005). Stigma has been documented as one of the key barriers to help-seeking among mental health patients (Clement, Schauman *et al.*, 2015).

A number of researches on mental illness and how it relates to stigma have been conducted (Weiss, Ramakrishna and Somma, 2006; Major & O'Brien, 2005). Public stigma is the most common type of stigma observed and studied, as it represents the prejudice and discrimination directed at a group by the larger population (Corrigan, Morris *et al.*, 2012). With regards to mental health, public stigma refers to a set of negative attitudes and beliefs that motivate individuals to fear, reject, avoid, and discriminate against people with such conditions (Corrigan & Penn 1999).

When there is an awareness of public stigma, the affected individual usually suffers from forms of self-stigma where the person internalizes feelings of guilt, shame, inferiority and the wish for secrecy (Watson, Corrigan *et al.*, 2007). Ergo, the person with the attribute subsequently internalizes the associated discredit thereby changing his or her own perception of the attribute (Watson, Corrigan *et al.*, 2007). Self-stigmatization which is a component of the broader social phenomenon stigmatization then sets in, thus, once these individuals have been labelled with an

undesirable characteristic. they accept and act accordingly (Bathje & Marston 2014). Self-stigma among persons with schizophrenia occurs when they internalize the negative public attitudes and suffer numerous adverse consequences as a result (Corrigan, Watson *et al.*, 2006). Corrigan and colleagues describe self-stigma as a process in which patients with schizophrenia internalize mental illness stigma and experience diminished self-esteem and self-efficacy (Corrigan, Watson *et al.*, 2006). Self-stigma can be an inhibiting factor that impedes help-seeking behaviors and the quality of treatment and life experienced by individuals with mental illness (Corrigan, 2004). Livingston and Boyd (2010) also reported the negative effects of self-stigma as causing severe psychiatric symptom severity and negatively associated with treatment adherence.

Stigma of caregivers of mental health

Goffman (1963) also described how the stigma process could extend to other people without the attribute but who are connected to the stigmatized person like relatives and psychiatric professionals, he referred to this as courtesy stigma. Fear of courtesy stigma results in concealment and secrecy of the condition by affected persons and this limits access to family support (Hinshaw, 2005). For instance a study on the experiences of stigma and discrimination among caregivers of persons with schizophrenia in China revealed that nearly 65% of caregivers reported that they tried to conceal their family members' illness because of the stigma they would encounter (Yin *et al.*, , 2014). Enacted and perceived stigma described by Jacoby (1994) are other forms of stigma which are key in understanding the impact of stigma on affected individuals or to other people without the attribute but who are connected to the stigmatized person like relatives. Enacted stigma is described as the experience of negative and discriminatory behavior by others against a person with a stigmatizing attribute and this will possibly be extended to their relatives (Jacoby, 1994).

CHAPTER THREE

METHODS

3.1 Study design

This chapter describes the research design and methodology. The research design and methodology includes the study area, study population, sample and sampling technique, data collection, analysis and ethical considerations. This study employed a qualitative research approach because it sought to unearth the lived experiences of stigma experienced by the study population. With this in mind, stigma experiences and factors that influenced stigmatization was explored in focus group discussions with the families of schizophrenic persons and in-depth interviews with schizophrenic persons.

3.2 Study Area

The study was conducted in the Kaneshie Polyclinic and Bubuashie within the Okai Koi South Sub Metro. The Okaikoi South sub-metro is one of the ten Sub-Metros of the Accra metropolitan Assembly in the Greater Accra. Accra is the capital town of the Greater Accra Region. The Okaikoi South Sub-Metro is made up of four major communities; Kaneshie, North Kaneshie, Bubiashie and Darkuman. The estimated population is about 121,718 people. The sub-metro is a densely populated urban area with its inhabitants being mostly traders, artisans and public servants. The Kaneshie Polyclinic is located within the Kaneshie Township; the polyclinic has a psychiatric unit where participants for the study were sampled from. There are about 20 other health facilities in the sub metro.

3.3 Study Population

The study population refers to the group the researcher wants to study into, from which study sample was drawn. Eligible participants included schizophrenic persons 18 years and above integrated into society and their family members above 18 years.

3.4 Sampling Method

This study employed purposive sampling method, which is a non-probability sampling procedure. It is a type of sampling where the researcher consciously selects particular elements or subjects to include in the study ensuring that those elements or subjects possess certain characteristics pertinent to the study. Schizophrenic persons, accompanied by their relatives or family members come for review in the psychiatric unit of the polyclinic. They and their family or relatives who accompanied them for the review were identified and informed about the research. Their willingness to participate was sought and a convenient date was scheduled to have a focus group discussion and in-depth interview with them when they came for review in the polyclinic.

3.5. Data Collection Techniques

Below are details on the two (2) main qualitative approaches which were used for data collection.

3.5.1 In-depth Interviews (IDI)

In-depth Interviews (IDIs) were conducted using an interview guide. The IDIs were conducted among schizophrenic person identified in the polyclinic. A total of eight in-depth interviews were conducted; three among schizophrenia patients and five patients' relatives. Some of the

interviews were conducted in English, Twi and Ga Languages respectively. The interviews were audio recorded. The interview lasted for about 30-40 minutes.

3.5.2 Focus Group Discussion (FGDs)

Focus Group Discussion (FGD) is a qualitative data collection approach in which one or two researchers and several participants meet as a group to discuss a given research topic (Mack, Woodsong, MacQueen, Guest, & Namey, 2005). Two focus group discussions (N=18) comprising of family members of different schizophrenic persons were conducted. With particular reference to the research's objective of ascertaining why family members of schizophrenic persons were being stigmatised and how they cope with it, focused group discussion was the appropriate method for family members to share their experiences. The interviews were audio recorded. The interviews lasted for about 40-60 minutes.

3.6 Data Collection Tool and Procedure

Focus Group Discussion (FGDs) and in-depth interview (IDIs) guides were used to collect data in this study. There were two different groups of people (schizophrenic persons). Each focus group comprised of eight participants. The guides were used to elicit experiences of stigma against schizophrenic persons. The local dialect Ga or Twi was used for data collection; however, participants who preferred English were interviewed as such. Data was collected by the principal investigator and well-trained research assistants.

3.7 Quality Control

To ensure good quality of data collection, the research assistant was trained on research ethics and taken through the interview guides. Each day, data collected was replayed and listened to by the principal investigator be to ensure that all information has been gathered properly. Errors and omissions detected were duly discussed with the research assistant and corrections were effected in subsequent ones.

3.8 Data Processing & Analysis

The data generated from the FGDs and IDIs were tape recorded and notes taken alongside. Interviews were then transcribed verbatim. Manual thematic content analysis was employed in the analysis of the data for this study. The transcribed data was read over and over again to identify words, concepts and themes that appeared frequently. Themes, concepts and words that were recurrent were identified and grouped into major themes and sub themes to reflect the emerging experiences of stigma of the participants.

3.9 Pilot Study

The study was piloted Pantang Psychiatric Hospital on schizophrenic patients and their family members. The pilot was to ensure that the questions asked are understood and clear enough to generate relevant responses as well as enable the researcher get familiar with the interview guides necessary modifications and clarification of terms were effected based on the pilot study procedure.

3.10 Training of research assistants

One research assistant with a degree in Public health and experience in qualitative research was recruited to help with the data collection. The research assistant was trained for a day in order to get familiar with the guides to be used. Training entailed explanation of the interview guides in English, Ga and Twi, ethics and seeking informed consent from study participants. This was to ensure that the research assistant collected valid and reliable data as well as conform to the ethical guidelines of the study.

3.11 Ethical Considerations

Ethical clearance from the Ghana Health Service Ethical Review Board was obtained before the commencement of the study. Permission was also obtained from the Ga Metropolitan Sub Metro, Okaikoi District and Kaneshie Polyclinic. The purpose of the study was explained to participants and their verbal and written consent were taken. Names were abbreviated to disguise the participants' identity. Confidentiality was ensured by not disclosing any of the data collected on participants deliberately or accidentally to other people. Study participants were informed of their right to withdraw from the study at any point in time if they so pleased.

CHAPTER FOUR

RESULTS

This chapter presents results on the characteristics of the study participants and themes that emerged from the In-depth interviews and focus group discussions with family and persons with schizophrenia. From the experiences narrated by persons with schizophrenia and their care givers, three main themes and 6 sub themes emerged from the data analysis. The three main emergent themes included perceived causes of schizophrenia, experiences of stigma by family members and persons with schizophrenia and family burden.

4.1 Characteristics of Participants

The study participants with schizophrenia who participated in the focus group discussions were 18 in number, with each focus group comprising of nine participants. The focus group comprised of both sexes and they were aged between 24 to 85 years. Most (8) of them were unemployed, five (6) of them were traders, two (2) of them were seamstresses and the remaining two were poultry and electrical engineer respectfully. In terms of their marital status, eleven (15) of them had never married, one was divorced, another a widow and the remaining one was married. Family members who were caregivers of the patients comprised of mothers, fathers, sisters, and brothers

4.2 Perceived causes of schizophrenia

Schizophrenia was perceived to be caused by supernatural forces. Caregivers and persons with schizophrenia attributed the condition to family curses, demonic attacks and evil machinations by their enemies. It was perceived that the condition was due to curses invoked on some family

members for wrongs they have done to other people. Therefore the people suffering from the condition are paying for the wrongs their family members have caused. Other narratives also revealed the curses to be from spiritual leaders like pastors. Furthermore, schizophrenia was perceived to demonic attacks by family members who are idol worshippers. Participants were also of the opinion that when Satan sees the destiny God has given you, he can decide to destroy your bright destiny by giving you this disgraceful condition to destroy it, so prayer is needed to revert such demonic attacks by the devil. The perception that that schizophrenia is a spiritual disease was evidenced in statements made by these participants.

> *"Hmmm, my brother was cursed by a pastor. It is a long story that I don't want to remember but he was cursed by a pastor and them the problem started so a neighbor even knew the said pastor who cursed him led us to him. We don't do anything fetish. So we took him to the pastor. He prayed for him and lifted the curse from him"- (*IDI, brother of a person with schizophrenia*).*

> *"My daughter was very intelligent is school, very respectful and then she just started insulting her father and myself and then now they say she has this mental problem. I know she has a bright future but the devil wants to destroy it, I will not allow it. I have been praying and I know God will finally answer me"-(*IDI, Mother of a person with schizophrenia).

> *"I didn't know the cause of my problem until I came to Ghana and my aunties told me it has do with a curse that was placed on her by a woman that my father was initially going to marry. So I was more curious and told my dad about it and he said that if it was true and that we should find a solution it. So in mother's family they have one fetish who consults the sea and she confirmed that what has been said is true and that curse was placed on my mother and that it is high time we reversed it. So my dad was like if he knows the prize and all that he is ready to revert it. Schizo" (***FGD, Person with schizophrenia).

> *"We don't originate from here, we come from Togo but my sick younger brother was born here in Ghana. My parents left Togo because of the family they come from they are idol worshippers and they do a lot of bad things. Even though we*

*left there (Togo) they have still managed to get to us because we believe our family responsible for what is happening to him. He was very intelligent, and even wanted to become a fireman"- (*IDI, brother of a person with schizophrenia)

Perception that the disease is as a result of a curse on the family resulted in the family and persons with schizophrenia being stigmatized and discriminated against. Family members were either insulted or pointed to as cursed. Also, some of the family members said people shun their company because they don't want to associate themselves with cursed people lest they become cursed too. These are presented in the quotes below;

*"The people in our area have been saying that our family has been cursed with madness, so when I hear this I feel very sad"-(*IDI, Sister of a person with schizophrenia).

*"One day I was in my room in the house and I heard one of the tenants in the house telling her daughter not to play with my brother because there is a bad thing in the family that is attacking us and that is why my brother is behaving like a madman"- (*IDI, sister of a person with schizophrenia*)*

The perception that schizophrenia is due to supernatural causes influenced the care sought. This is because some of the patients were taken to prayer camps and shrines in attempts to cure or heal the person from the condition.

*"Some people say that this is a spiritual problem so I should take him to the fetish priest some also said prayer camps. I have roamed from prayer camp to prayer camp and finally I had to bring him to the psychiatric hospital again"- (*IDI, mother of a person with schizophrenia*).*

*"Yes, I do it very often. I ask them if they have any solution to her condition because I think it brings a lot of shame to the family and my children. (He looked away). Some also tell me her condition is spiritual. They also advice that I take her to a prayer camp for deliverance."-(*IDI, brother of a person with schizophrenia)

"We are Christians but when certain things happen to you, you will be forced to go to places you never thought you could go. I had a lot of people telling me that mental problems are evil and spiritual attacks from my family, community or even my work place. So I took my son to churches but nothing was happening, so then I took him to this shrine in the eastern region, there too nothing. Hmmm, so now we come to the hospital"-(IDI, father of a person with schizophrenia)

4.3 Experiences of stigma by persons with schizophrenia and their family members

Schizophrenic persons and their family members suffer different forms of stigma. The recurrent ones in this study ware offensive name callings, ridicule and mockery as well as avoidance by society members.

4.3.1 Offensive name callings

Derogatory names callings of persons with schizophrenia were a common stigmatizing attitude reported by both family and persons with schizophrenia. Mainly, offensive names used for persons with schizophrenia "bodamfuo and sekeyelor" which means madman or lunatic in the local dialect Twi and Ga respectively. Although, the family members were not referred to directly as mad people or lunatics, names or comments such as "family of mad people" and "people with torn brain cords" are offensive and these were reported by the family members. These name callings usually come about when there is a misunderstanding between the schizophrenic person or the family members and their community members. These derogatory names by which they are referred to cause them anguish, hurt and shame.

"My friends used to call me names like "crazy maputu" when I was young and I throw stones at them" (FGD, person with schizophrenia).

" when my brothers condition started, it was very bad he left the house as was very violent and he was begging for food on the streets, but now he is better and

*he is home but people still refer to him as bodamfuo (madman). I don't know why they do that because he is now normal."-(*IDI, sister of person with schizophrenia)

*"We don't like to disclose my sisters condition to people because some of the people who know her refer to her as sekeyelor (meaning mad person) or cursed so we like to keep it" (*IDI, family member #3*).*

*"it was from a neighbor who insulted me about my mother's condition when we had an argument. She said I came from a family of mad people so that is why I behave like one. I was very hurt"-(*daughter of a person with schizophrenia*)*

4.3.2 Ridicule, mockery and gossip

Family members of persons with schizophrenia recounted instances where they were laughed or pointed at because of the condition suffered by their relations. They explained how uncomfortable and shameful these behaviors are to them and these are quoted below.

*"They make fun of me. They say that since I have an aunt who's mad, I'm also mad. Sometimes when I'm angered and I react they say I'm imitating my aunt's 'madness'. When that happens I just walk away because I don't want to get into a fight"-(*IDI, daughter of a person with schizophrenia*)*

"I feel really bad, because people keep pointing fingers at us when we come out of the house, and it's very embarrassing, so we don't like talking about it"

*"Everything is alright except the mockery from friends that bothers me... They insult us with it, they call us the mad woman's children and call us mad too... You just have to take heart in these things and move on"-(*IDI, Son of a schizophrenic person)

4.3.3 Alienation from society

Another form of stigma experienced by persons with schizophrenia is their alienation from society. Some of the patients recalled how their family members refuse to eat with them and this was a source of worry for them. Other schizophrenic persons also recounted how they were

avoided in social gatherings including the church. Family members also had their fair share of societal avoidance and these were evident in the strained relationships they observed from some community members.

> *"Sometimes I feel like I want to hit my head with stone. Friends and family don't want to eat with me but I don't know why"*-(IDI, person with schizophrenia).

> *"At first I did not notice that people didn't want to sit by me in church. But later I realized that even when there is space by me, they go and sit somewhere else and they only come to sit by me when the whole church is full and there is no other space. After seeing that, I just stopped going and I pray at home"* – (FGD, person with schizophrenia)

> *"We don't like to talk about it because it doesn't bring any good feeling and because of the stigma attached to it. When people get to know they don't want to associate with you or the family. And people are gossips too"* - (IDI, sister of person with schizophrenia)

4.4 Social isolation and withdrawal due to public stigma

Family members of persons with schizophrenia withdraw society and avoid going for social gatherings because they feel ashamed and do not want to be questioned about their family members' mental state. These were the opinions shared by some family members as is evident in the quotes below:

> *"Because of what was happening I don't go anywhere again. I used to be a choirister in church because of this I don't go to church, I feel disgraced. I don't want people asking me what the problem is with my child"*-(IDI, mother of schizophrenic person)

> *"I don't go for things like engagement and outdooring because people point fingers at me that I can't help my sister to get well but I've dressed up for an occasion so because of those bad things I don't go at all"* (IDI, sister of person with schizophrenia)

"We the family members are always home, except when there're social activities like funerals. Even, with that, the relationship with the community is not as strong they look at you in a way that is demeaning so sometimes I don't go for these programs because you don't feel accepted among them so I just stay in the house"-(IDI, sister of person with schizophrenia)

4.5 Burden of family members

The burden experienced by family members of persons with schizophrenia involved psychological, social and economic burden. Psychologically they expressed sentiments like sadness, worrying and shame about the condition of their family member. Furthermore, the need to be with them constantly affects their income generating work because some of them had to quit their jobs or absent themselves frequently thereby limiting the income they used to get. Furthermore, the cost of care, in terms of visiting the hospital and buying medications also adds to the toll of the financial burden.

4.5.1 Psychological burden

Relatives of patients with schizophrenia have to go through psychological distress. Respondents mentioned that they were worried about how care for the patient now and after they have died. Relatives were also concern about the possibility of patients getting better and even getting married as illustrated:

"I am not comfortable or a happy person at all, because when the whole thing started and I got to know it was a very difficult for me. How can a mother take it when her son is said to have a mental problem. I was always crying"-(IDI, mother of a person with schizophrenia)

"Hmmmm, it is very shameful, you know how Ghanaians feel about mental illnesses, they think it is a family thing and that we all have it so it brings a lot of shame to the family and my children. (He looked away)"-(IDI, brother of person with schizophrenia).

*"I have not been myself since I found out about my sons mental problem, I think and worry about so many things, I am worried about who will care for him when I am no more, will he ever get married, all these are my worry"-(*IDI, mother of person with schizophrenia)

4.5.2 Economic burden

Family members expressed sentiments of disappointment knowing they had spent so much money on their children only for them to be diagnosed with a mental condition. Furthermore, family members had to quit their jobs or reduce working hours to enable them care for their family members these are evidenced in the quotes below;

*"We felt really bad and disappointed after the diagnosis came out because we had invested a lot in her"-(*IDI, father of person with schizophrenia*).*

*"She's my first daughter we have wasted money on her and then this happen, aaaahhh you won't feel fine. The whole family doesn't feel fine"-(*IDI, mother of person with schizophrenia)

*"I used to sell salad leaves in the market but I am not able to go and sell anymore because I have to care for my mother. So I decided to sell some foodstuffs in the house but you know that I will not be able to make as much money as I was doing when I go to the market, even the little money I get that is what we use to eat and buy her medicines"-(*IDI, daughter of person with schizophrenia)

CHAPTER THREE

5.1 Discussion

Mental illnesses attract a lot of stigma (Babic 2010). However schizophrenia is one of the most stigmatized mental conditions (Van Zelst, 2009) because of its perceived dangerousness and unpredictability (Levey, Howells *et al.*, 1995). The stigma experienced by people with mental illnesses can hinder help-seeking behaviors further exacerbating their condition (Corrigan, 2004). This study sought to find out the experiences of stigma among the family and persons with schizophrenia in the Okaikoi South District. The results from the study revealed the different perceived causes of schizophrenia, experiences of stigma by schizophrenic persons and their family members as well as the burden they suffer. The experiences of stigma were in the form of offensive name callings, mockery and ridicule, alienation from society.

Findings from this study revealed that mental ailments were generally perceived to be caused by supernatural forces. Participant named demonic causes, curses and evil machination by idol worshipping family members. Hailemariam (2015) explains that West Africans have voodoo and witchcraft embedded in their culture therefore they usually attribute mental illnesses to supernatural causes. In his study on perceived causes of mental illness and treatment seeking behaviours among people with mental problems discovered that people with mental illnesses ascribed their condition to malevolent forces as well as perceived it to be a punishment from God for disobeying religious ethics and social prohibitions (Hailemariam, 2015). The findings from this current study can be related to the assertion by Hailemariams (2015), because Ghana is a West African country with voodoo and witchcraft present in its cultural beliefs. Similarly, Kuppin and Carpiano (2008) also reported that the perception that mental illnesses is due to

supernatural causes is a common belief held by most Nonwestern cultures as opposed the perception held by Western cultures who attribute mental ailments to biological and psychosocial causes. In the same way, a qualitative study by Teferra & Shibre (2012) on the perceived causes of severe mental disturbance and preferred interventions by the Borana semi-nomadic population in southern Ethiopia revealed supernatural causes of mental illnesses as possession by evil spirits, curses and acts of witchcraft. These perceptions about the supernatural causes of mental illness are evidence of the fact that there is a grave lack of factual knowledge about mental illnesses and its causes in African populations.

Spiritual perceptions about mental illness strengthen the popularity of the shrines and churches, since they attend to issues pertaining to evil spirits and witchcraft. Therefore, family members of persons with schizophrenia in this study were advised to send the patients to prayer camps and some of them did. It is a common practice for family members to seek care from shrines and prayer camps in Ghana. This is evidenced in an ethnographic study by Read, Adiibokah *et al.*, (2009), where some of the family members stated that they did not see improvement when they sought orthodox care thus they resorted to prayer camps and shrines since the condition is perceived to be caused by spiritual forces.

Stigma of mental health conditions with schizophrenia inclusive is not a new phenomenon and this was the case of persons with schizophrenia as well as their family members in this study. Persons with schizophrenia in this study were subjected to derogatory name callings like *bodamfuo* and *sekeyelor* in local languages which are synonymous to a lunatic or mad man. This form of stigmatizing attitude of derogatory name calling is reported in both developed and developing countries (Botha, Koen *et al.*, 2006; Rose, Thornicroft *et al.*, 2007; Read, Adiibokah

et al., 2009). A study in Britain among adolescents reveled that mentally ill persons were called offensive names like looney bin, brain dead, psycho, nuts and even schizophrenia (Rose, Thornicroft *et al.*, 2007). Likewise, Read, Adiibokah *et al.*, (2009), reported name callings like "***bodamfuo***" and "***sekeyelor***" in their study.

Alienation from society was reported by persons with schizophrenia as well as their family members. This societal avoidance could be due to the notion that the condition is as a result of a curse because people don't want to be associated with cursed people. Also, the perception that people with schizophrenia are dangerous could account for the alienation because some of the participants were reported as violent, thereby sparking public avoidance. Our findings are in tandem with the study by Skulze (2003) who also found that schizophrenic patients were avoided by their neighbors after they got to know about their condition. Correspondingly, a study on the perceptions of mental and physical illnesses in north-western Ethiopia also revealed that people generally avoided people with some disease conditions with schizophrenia, leprosy and tuberculosis ranking highest among the diseases stigmatized (Mulatu, 1999).

Stigma by association, where an individual is stigmatized because relationship or link they have with someone with a stigmatizing trait (Goffman, 1963). This stigma by association was not only a worry by family members in this study but they were also stigmatized against. This made them shy away from social gatherings thus withdrawing from social functions like church going or attending weddings and funerals. Quinn (2007) reported that that many relations of mentally ill persons were persistently worried about being stigmatized in his study on the stigma of mental illness in Southern Ghana. Phillips, Pearson *et al.*, (2002) in their study on experiences of stigma by persons with schizophrenia and their family members revealed that their family members also

avoided social gatherings and resorted to keeping the condition a secret to avoid being stigmatized.

Family members reported psychological and financial burden associated with caring for their relations with schizophrenia. This is to be expected, because the cost of mental health care in developing countries is relatively expensive (Saxena, Thornicroft *et al.*, 2007). Besides mental conditions like schizophrenia is not covered under the Ghana Health insurance Scheme so this explains the financial burden it poses of family members. Sickness of any form is a source of worry for everybody therefore; mental illness which is highly stigmatized will impose a grave psychological burden on family members as seen in this study.

This study conceptualized that persons with schizophrenia will be avoided by others, gossiped about, feared and discriminated against and this result in them being stigmatized. Similarly, it was conceptualized that their family members would be avoided, gossiped about and pitied. The findings from the results corroborate what was conceptualized because persons with schizophrenia were avoided by society, gossiped about likewise their family members.

CHAPTER SIX

SUMMARY, CONCLUSIONS AND RECOMMENDATION

6.1 Summary of Findings

This study sought to find out the experiences of stigma among family and persons with schizophrenia in the Okaikoi South district. With the objective of finding out the stigma persons with schizophrenia and their family experience, a qualitative research method was employed. Two focus group discussions (N=18) and eight in-depth interviews were used to elicit responses on the experiences of stigma. The main study findings include:

1. The study revealed that schizophrenia was to be caused by supernatural forces. It was the view of participants that people get schizophrenia because of curses, evil machinations and demonic attacks and such people are afraid of people who have the condition and their family members.
2. The study further revealed that people with schizophrenia and their relatives are stigmatised at the community. To escape from this stigma as well as the beliefs that it was a spiritual condition, patients are sent to prayer camps and shrines.
3. The study furthermore reports that stigmatization of patients with schizophrenia come in the form of offensive name callings, alienation from society, being ridiculed or mocked.
4. Due to these stigmatizing attitude, family members and persons with schizophrenia avoided social gatherings like funerals, wedding and naming ceremonies. The family members also revealed the burden they suffer due to the caregiving role. They named psychological sufferings in the form of worrying and fear as well as financial burden due to their inability to fully engage in income generating activity and the cost of hospital bills they incur.

6.2 Conclusion

Schizophrenia is believed to be spiritual mental health condition and stigmatization of patients with schizophrenia and their relatives was common in the community. As a result of the stigma both patients and relative stay away from public gathering and resort to spiritual healers for health care.

6.3 Recommendations

1. The mental health authority should intensify health education on schizophrenia. This will create awareness of the causes of schizophrenia and reduce the fear and stigmatization associated with it.
2. The mental health authority should collaborate with prayer camps and other spiritual healing centres in communities as such centres could be used to identify patients and put them on treatment.
3. Mental health conditions should be factored in the Ghana Health Insurance Scheme to enable better health seeking behaviour of persons with mental health.

6.4 Limitations of the study

The study sought to conduct more than two focus group discussions among persons with schizophrenia, however, the researcher was unable to get more patients as the number of people with the condition were limited based on the hospital records from which they were contacted. Additionally, translation of some terminologies from English to the local languages such as Twi and Ga during the interview might have distorted the meaning. Hence the finding of this study is limited in scope. This notwithstanding, it provides an understanding on the experience of stigma among patients with schizophrenia and their relatives.

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Appendix: Consent Form

FOCUS GROUP DISCUSSIONS AND IN-DEPTH INTERVIEWS AMONG SCHIZOPHRENIC PERSONS AND THEIR FAMILY MEMBERS

Title of study: experiences of stigma among family and persons with schizophrenia in the okaikoi south district

Introduction and nature of the study: Good day! My name is.....and I am from the School of Public Health, University of Ghana, Legon. I am conducting a study to find out the **Experiences of stigma against persons with schizophrenia in the okaikoi south district**. Schizophrenia is named as one of the mental illnesses in the world and it attracts a lot of stigma. If you decide to participate, we will ask you to participate in a discussion/interview about your experiences of stigma. The interview is expected to last 30-40 minutes.

Possible Risks and Discomforts

We do not anticipate any physical risk for participating in the study. The topics discussed during the interviews may be sensitive and may be uncomfortable for you to discuss. During the interview, you do not have to answer any questions that you do not want to answer. If you are not comfortable with the questions asked, you can withdraw from the study at any time. Your participation in the study will not affect your right to health care provision.

Possible Benefits

Though there is no direct benefit to you as an individual, your participation will help in making policy recommendations with regards to stigma of mental health illnesses especially schizophrenia

Additional Cost

There is no cost for participating in this study.

Compensation

There will be a reimbursement for travel costs the participants may incur while taking part in the study and the focus group discussion members will be refreshed with non-alcoholic beverages and snacks.

Confidentiality

All of the information that we collect during the study including any personal information about you will be confidential. We will not write your name on any of the information we collect and your personal information will be stored separately from study data. We will assign you an identification number and only this number will link you to the data we collect. Only study personnel will have access to the data, which will be kept in a secure location and password protected computer. This information will be destroyed two years after completion of study. No paper trail is stored.

Voluntary Participation/Withdrawal

Your participation is completely voluntary. You have the right to withdraw from the study at any time by notifying the study personnel.

Alternatives to Participation

Your participation in the study is completely voluntary. The alternative is not to participate in the study.

Contacts for Clarification

If you have any questions about the study, you can contact the principal investigator, Jessica Owoo on 024-6854533 (email address: topazruby28@gmail.com); the study primary supervisor,

Dr Emmanuel Asampong (email address: easampong@ug.edu.gh); or the secretary to the GHS Ethical Review Committee, Madam Hannah Frimpong on 0507041223.

VOLUNTEER AGREEMENT

The above document describing the purpose, benefits, risks and procedures for the study has been read and explained to me. I have been given an opportunity to have any questions about the research answered to my satisfaction. I agree to participate as a volunteer.

_____ _____

Date Name and signature/mark of volunteer

If volunteers cannot read the form themselves, a witness must sign here:

I was present while the purpose, benefits, risks and procedures were read to the volunteer. All questions were answered and the volunteer has agreed to take part in the research.

_____ _____

Date Name and signature of witness

I certify that the nature and purpose, the potential benefits, and possible risks associated with participating in this research have been explained to the above individual.

_____ _____

Date Name and Signature of Person Who Obtained Consent

INTERVIEW GUIDE ON EXPERIENCES OF STIGMA AGAINST PERSONS WITH SCHIZOPHRENIA IN THE OKAIKOI SOUTH DISTRICT (focus group discussion)

1. Demographic Data: Age, Occupation, Marital status, Number of Wives, Number of children, Educational level, Professional background (To be taken on a separate sheet prior to FGDs)

2. Please, what condition are you suffering from?
3. How did you feel the first time you knew you were suffering from the condition?
4. Have you disclosed your condition to friends or acquaintances?
   (a) Probe who they were
   (b) Probe what were their reactions?
5. How do you feel about talking about your condition with friends or acquaintances?
6. Have you made any changes in your social networks?
7. If you are not participating socially, what are the major reasons for not taking part in activities?
8. What are you actively doing to manage or deal with any restrictions in your social participation?
9. Do your family members treat you differently since the diagnosis of your condition?
   (a) Probe If yes, in what ways?
10. Have friends and acquaintances treated you differently since your diagnosis of your condition?
    (a) Probe if yes, in what ways

11. [redacted] reactions or responses from others due to your [redacted] condition?

We are now finished with my questions. Thank you very much for taking the time to speak with me today. Is there anything else you will like to add?

INTERVIEW GUIDE ON EXPERIENCES OF STIGMA AGAINST PERSONS WITH SCHIZOPHRENIA IN THE OKAIKOI SOUTH DISTRICT (In-depth interview)

1. Please, what condition is your family member suffering from?
2. How did you feel the first time you heard about it?
3. How do you feel about talking about your family member's diagnosis with friends or acquaintances?
4. Have you disclosed your family member's diagnosis to friends or acquaintances?
   (c) Probe who they were
   (d) Probe what were their reactions?
5. Are you comfortable disclosing or discussing you family member's diagnosis with others?
6. Have you made any changes in your social networks?
7. If you are not participating socially, what are the major reasons for not taking part in activities?
8. What are you actively doing to manage or deal with any restrictions in your social participation?
9. Do other family members treat you differently since the diagnosis of your family member?
   (b) Probe If yes, in what ways?
10. Have friends and acquaintances treated you differently since your family member's diagnosis?
    (b) Probe if yes, in what ways

[redacted] any negative reactions or responses from others due to your family member's diagnosis?

We are now finished with my questions. Thank you very much for taking the time to speak with me today. Is there anything else you will like to add?

GHANA HEALTH SERVICE ETHICS REVIEW COMMITTEE

Research & Development Division
Ghana Health Service
P. O. Box MB 190
Accra
Tel: +233-302-681109
Fax + 233-302-685424
Email: ghserc@gmail.com

In case of reply the [illegible] and date of this [illegible] should be quoted.

[illegible] GHS/RDD/ERC/Admin/App/17/433
[illegible] Ref. No.

[illegible] Owoo
[illegible]versity of Ghana
School of Public Health
Legon, Accra

The Ghana Health Service Ethics Review Committee has reviewed and given approval for the implementation of your Study Protocol.

GHS-ERC Number	GHS-ERC: 134/02/17
[illegible] Title	Experiences of Stigma among Family and Persons with Schizophrenia in the Okaikoi South District
Approval Date	2nd March, 2017
[illegible] Date	1st March, 2018
GHS-ERC Decision	Approved

This approval requires the following from the Principal Investigator

- Submission of yearly progress report of the study to the Ethics Review Committee (ERC)
- Renewal of ethical approval if the study lasts for more than 12 months,
- Reporting of all serious adverse events related to this study to the ERC within three days verbally and seven days in writing.
- Submission of a final report after completion of the study
- Informing ERC if study cannot be implemented or is discontinued and reasons why
- Informing the ERC and your sponsor (where applicable) before any publication of the research findings.

Please note that any modification of the study without ERC approval of the amendment is invalid.

The ERC may observe or cause to be observed procedures and records of the study during and after implementation.

Kindly quote the protocol identification number in all future correspondence in relation to this approved protocol

SIGNED.....
DR. CYNTHIA BANNERMAN
(GHS-ERC CHAIRPERSON)

The Director, Research & Development Division, Ghana Health Service, Accra