



PhD thesis

**Supporting people diagnosed with schizophrenia living in the community and their caregivers: the Ghanaian perspective**  
**Asamoah, G.**

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**SUPPORTING PEOPLE DIAGNOSED WITH SCHIZOPHRENIA  
LIVING IN THE COMMUNITY AND THEIR CAREGIVERS: THE  
GHANAIAN PERSPECTIVE**

**A thesis submitted to Middlesex University in partial fulfilment of  
the requirements for the degree of Doctor of Philosophy**

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## **ABSTRACT**

The transition from hospital-based to community-based mental health services in Ghana has faced significant obstacles due to insufficient resources and a lack of social support for both service users and their caregivers. Schizophrenia is recognised as one of the top 20 disease burdens globally, and mental disorders are major contributors to disability. Although the overall incidence of schizophrenia is low, its impacts on service users, families, and society are profound. The ramifications of schizophrenia often include social isolation, feelings of worthlessness, and a diminished social status, stemming from the individual's inability to fulfil socially defined roles.

Despite existing research, there is a notable gap in the literature concerning schizophrenia and the support available to affected individuals and their families within Ghana's community mental health services. Consequently, this study aims to explore the support mechanisms in place for individuals diagnosed with schizophrenia and their caregivers living in Ghana. This exploration focuses on the perceived meaning of support for service users, the nature of professional care provided to community mental health service users, the experiences of nurses working in the community mental health setting, the challenges facing community mental health services, and the appropriateness of services offered to caregivers.

**Methodology:** This study employed a qualitative approach, utilising interpretative phenomenological analysis (IPA) aided by the conceptual frameworks of the ecological model for health promotion (EMHP) and ladder of citizen participation. A purposive sample of 10 community service users diagnosed with schizophrenia, 21 caregivers of these individuals, and six community mental health nurses was recruited. Participants shared their lived experiences regarding the support of service users and their caregivers through in-depth interviews. The interviews were audio recorded and subsequently transcribed for thematic analysis.

**Findings:** The findings indicate that support for service users encompasses three dimensions: general, physical, and psychological. Furthermore, professional support was identified to consist of care reviews, assessments of service user needs, health promotion initiatives, access to medication and treatment, and counselling. Within the experiences of nurses providing care in community mental health settings, the study revealed numerous challenges, including a lack of free psychotropic medication for service users, inconsistent staff training, stigmatising attitudes toward mental disorders, and transportation difficulties for mental health

nurses. Additionally, the services available to caregivers were often inadequate or non-existent, rendering them unsuitable.

To address these issues, the study recommends several actions, including policy reform to improve caregiver assessment processes, provision of free psychotropic medication, enhancement of caregiver group support, transportation provisions for nurses, establishment of resource centres, implementation of proactive mental health crisis teams, and a review of education and training for nurses.

**Conclusion:** The burden of caregiving on caregivers is significant. Recognising the significant burden placed on families in caregiving, gaining a deep understanding of the real challenges faced by service users and their relatives will enhance the quality of care they receive. Therefore, it is crucial to proactively identify and address the needs of both service users and their caregivers to ensure they receive the necessary and appropriate support. Introducing a social dimension into community mental healthcare will be crucial in mobilising resources within the community to enhance the wellbeing of service users and their relatives. This approach will also strengthen the delivery of community healthcare services by actively involving both service users and their caregivers, contributing to the overall rehabilitation of community mental health. The study recommends a comprehensive policy planning and implementation that emphasises resource allocation for health supplies, staff training, and caregiver group support. This innovative approach has the potential to inspire a review and establishment of community mental healthcare services that are truly effective and suitable for the context of Ghana, with implications potentially extendable to other similar nations in Africa.

## **Dedication**

This thesis is dedicated to my late parents and brother-in-law: Godfried Kwaku Manu Asamoah, Elizabeth Sefa Asamoah and Clement Boakye.

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## Contents

<b>ABSTRACT</b> .....	ii
<b>Dedication</b> .....	iv
<b>Acknowledgement</b> .....	v
<b>List of tables</b> .....	xii
<b>List of figures</b> .....	xiii
<b>List of Abbreviations:</b> .....	xiv
<b>Glossary:</b> .....	xiv
<b>CHAPTER ONE: BACKGROUND</b> .....	<b>1</b>
<b>1.1: Introduction</b> .....	1
<b>1.2: Challenges to Community Mental Health services</b> .....	3
<b>1.3 Statement of Objective</b> .....	5
<b>1.4: Research Aim and Objectives</b> .....	6
<b>1.4.1: Research Aim</b> .....	6
<b>1.4.2: Research Objectives</b> .....	7
<b>1.5: Conceptual Framework and Community mental health services</b> .....	7
<b>1.6: Motivation for the Study</b> .....	15
<b>1.7: Outline of thesis chapters</b> .....	16
<b>1.8: Chapter summary</b> .....	17
<b>CHAPTER TWO: LITERATURE REVIEW</b> .....	<b>18</b>
<b>2.1: Introduction</b> .....	18
<b>2.2: Literature search methods and processes</b> .....	18
<b>2.2.1: The Population, Interest and Context (PICO) framework</b> .....	18
<b>2.2.2: Eligibility: Inclusion and exclusion criteria</b> .....	20
<b>2.2.3: Literature searches</b> .....	21
<b>2.2.4: Search results</b> .....	21
<b>2.2.5: Themes derived from the Literature Search</b> .....	23
<b>2.3: Literature Themes in More Depth</b> .....	24
<b>2.4: Diagnosis of Mental Disorders</b> .....	27
<b>2.4.1: What is not Schizophrenia?</b> .....	28
<b>2.4.2: What is Schizophrenia?</b> .....	28
<b>2.4.3: Prevalence of Schizophrenia Worldwide</b> .....	29

2.4.4: Causes of Schizophrenia .....	29
2.4.5: Treatment of Schizophrenia and Psychosis .....	32
2.4.6: Challenges of schizophrenia to society .....	33
2.5: Mental health context in Ghana.....	37
2.5.1: Brief Overview of Ghana .....	37
2.5.2: Mental Health Policy and Legislation in Ghana.....	41
2.5.2a: Lunatic Asylum Act (1888) .....	41
2.5.2b: The Mental Health Decree of 1972 (National Redemption Council Decree, NRCD 30).....	43
2.5.2c: The Mental Health Act of 2012 (Act 846) .....	44
2.6: Mental Health Facilities, resources, and financing.....	46
2.6.1: Mental Health Facilities .....	47
2.6.1a: Mental Hospitals .....	47
2.6.1b: Community Mental Health in Ghana.....	49
2.7: Human resource Capacity in Mental Health Service .....	51
2.8: Impact of Financing Difficulties .....	53
2.9: The Mental illness in Ghana .....	56
2.9.1 Schizophrenia: Ghanaian context .....	57
2.9.2: The cultural context of mental health care in Ghana.....	59
2.9.3: Traditional Approach to treating Mental Illness in Ghana .....	61
2.9.3a: Concoction .....	62
2.9.3b: Divination .....	62
2.9.3c: Rituals to Appease the Gods .....	63
Summary .....	64
<b>CHAPTER THREE: METHODOLOGY .....</b>	<b>66</b>
3.1: Introduction.....	66
3.2: Qualitative Research Design .....	66
3.3: Framework: Ontological and Epistemological Stance .....	66
3.3.1: Ontological Position .....	67
3.3.2: Epistemological stance .....	68
3.4: Why Phenomenology? .....	68
3.5: Hermeneutic Phenomenology .....	70
<b>CHAPTER FOUR: METHODS OF THE STUDY .....</b>	<b>73</b>
4.1: Introduction.....	73
4.2: Research Governance in Healthcare .....	73

<b>4.3: Entering the Field</b> .....	74
<b>4.3.1: Access to organisations and participants</b> .....	74
<b>4.3.1a: Role of gatekeepers in the current study</b> .....	74
<b>4.3.1b: Seeking Informed consent</b> .....	80
<b>Summary</b> .....	81
<b>4.4: Researcher Positionality: An in-between (Insider-Outsider) Researcher</b>	82
<b>4.5: Research Setting</b> .....	86
<b>4.6: Sampling and Recruitment of the Participants</b> .....	88
<b>4.6.1: Inclusion and Exclusion Criteria</b> .....	89
<b>4.6.2: Recruitment of Service User Participants</b> .....	90
<b>4.6.3: Recruitment of Caregivers</b> .....	91
<b>4.6.4: Recruitment of Nurses</b> .....	92
<b>4.7: Semi-structured Interview Guide</b> .....	94
<b>4.8: Piloting of the Study</b> .....	101
<b>4.9: Recording the Interview</b> .....	103
<b>4.10: Analytic Process: Transcribing interviews</b> .....	104
<b>4.11: Translation and Back Translation of Transcripts</b> .....	105
<b>4.12: Stages of back-translation of Semi-structured Guide</b> .....	107
<b>4.13: Researcher’s Role in Data Collection</b> .....	108
<b>4.14: Qualitative Data Analysis</b> .....	109
<b>4.15: Data Analysis in the Current Research</b> .....	111
<b>4.16: Coding in Interpretative Phenomenological Analysis</b> .....	113
<b>4.16.1: The manual stage</b> .....	114
<b>4.16.2: Qualitative Data Analysis Software (QDS)- NVivo</b> .....	114
<b>Summary and conclusion</b> .....	117
<b>CHAPTER FIVE: FINDINGS FROM SERVICE USERS, CAREGIVERS AND NURSES</b> .....	<b>118</b>
<b>5.1: Introduction</b> .....	118
<b>5.2: Demographic characteristics- Participants of this study</b> .....	118
<b>5.2.1: Service User Participants</b> .....	118
<b>5.2.2: Caregiver Participants</b> .....	120
<b>5.2.3: Staff Nurse Participants</b> .....	123
<b>5.3: Themes</b> .....	124
<b>5.4: Theme A- Perceived Meaning of Support for service users</b> .....	125
<b>5.4.1: General View of Support</b> .....	125

5.4.2: Physical Meaning of Support.....	127
5.4.3: Psychological meaning of support .....	129
5.4.3c: Counselling .....	132
<b>5.5: Theme B- Nature of Professional Support for Community Service User</b> .....	<b>134</b>
5.5.1: Emotional and counselling support .....	134
5.5.2: Care review .....	135
5.5.3: Access to Medication/Treatment .....	137
5.5.4: Public Health Education/Health Promotion .....	139
<b>5.6: Theme C- Nurses experience of caregiving .....</b>	<b>142</b>
5.6.1: Counselling Support.....	142
5.6.2: Care review and Access to medication/treatment.....	143
5.6.3: Advocacy Service for service users.....	143
5.6.4: Challenges Facing the Community Mental Health Service .....	144
<b>5.7: Theme D- The Services Provided to Caregivers and Their Suitability..</b>	<b>153</b>
5.7.1: Access to medication/Treatment, Counselling (Advice), and Public Health/Health Promotion .....	154
5.7.2: Visitation reduces cost of travel .....	154
5.7.3: Assessment of caregiver needs .....	156
Summary of Findings .....	158
<b>CHAPTER SIX: DISCUSSION OF FINDINGS.....</b>	<b>160</b>
6.1: Introduction.....	160
6.2: Objective 1-To investigate support for people diagnosed with schizophrenia from the perspectives of individuals with the diagnosis, their caregivers, and the professional nurses.....	161
6.2.1: Physical Support.....	164
6.2.3: Psychological support.....	168
6.2.3.1: Emotional, spiritual, and counselling support .....	169
6.3 Objective 2- To examine the nature of support that community service users get from the community mental health service.....	175
To address Objective 2, this was facilitated using the finding or theme (b) the nature of professional support for community mental health service users. .....	175
Theme B- the nature of professional support for community mental health service users.....	175
6.3.1: Care Review for Service Users .....	175
6.3.1b: Health promotion for service users.....	181

6.3.1c: Counselling.....	182
6.3.2: Access to medication and treatment.....	182
6.4: Objective 3- To investigate the nurses' experience of caregiving in the community setting.....	184
6.4.1: Nurses experiences of caregiving.....	184
6.4.1a: Lack of free psychotropic medication.....	185
6.4.2: Addressing the Challenges Facing Mental Health Nurses.....	187
6.5 Objective 4- To investigate the services the caregivers of community service users are currently receiving and to establish what they consider to be appropriate support in the community.....	191
Theme D- the services provided to caregivers and their suitability.....	191
6.5.1: Services caregivers receive from community mental services.....	192
Summary:.....	197
<b>CHAPTER SEVEN: RECOMMENDATIONS AND CONCLUSION.....</b>	<b>199</b>
7.1: Introduction.....	199
7.2: A review of the research question.....	199
7.2a: Objective 5 -To make recommendations concerning policy planning and implementation to enhance the provision of community mental healthcare service in Ghana.....	199
7.3: Policy planning and implementation.....	200
7.3.1: Policy Reform: with regards to caregivers' assessment.....	200
7.3.2: Free Psychotropic Medication.....	201
7.3.3: The value of Caregiver Group Support.....	202
7.3.4: Transportation for nurses.....	202
7.3.5: Resource Centres.....	203
7.3.6: Mental Health Crisis Teams.....	204
7.3.7: Review of Education and Training for nurses.....	204
7.4: Contribution to Knowledge.....	206
7.4.1: Conceptual framework contribution.....	206
7.4.2: Methodological contribution.....	206
7.5: Suggestions for further research.....	207
7.6: Conclusion.....	207
<b>APPENDICES.....</b>	<b>245</b>
Appendix 1- Middlesex University's Health and Education Ethics Committee Conditional Approval Letter.....	245
Appendix 2 - Middlesex University's Health and Education Ethics Committee Approval.....	246

Appendix 3 - Middlesex University's Health and Education Ethics Committee Amendment Approval (Additional participant group).....	247
Appendix 4- Director of Studies, Middlesex university's introductory letter to Ghana Health Service Ethics Committee .....	248
Appendix 6- Ethics approval by the Ghana Health Service Ethics Committee ...	250
Appendix 7- Ethics amendment Approval by the Ghana Health Service Ethics Committee .....	251
Appendix 8 – Participant Information Sheet (staff participants) .....	252
Appendix 9 – participant information sheet (service User and carers).....	258
Appendix 11 - Consent form for staff participants .....	264
Appendix 12- Interview guide for service users .....	265
Appendix 13- Interview guide for caregivers.....	267
Appendix 14- Interview guide for healthcare professionals.....	268
Appendix 15: Sample of conversation with participants.....	270
Appendix 16: Stages of back-translation of Semi-structured Guide.....	271
Appendix 17: Stages of Back-translation of transcription.....	272

## List of tables

Table 2. 1: PICO framework guiding search.....	18
Table 2. 2: Eligibility criteria .....	20
Table 2. 3: Database searches and returns.....	22
Table 2. 4: Professionals working in Mental Health Service in Ghana.....	52
Table 2. 5: Prevalence and Treatment Coverage of selected Mental Disorders. ....	58
Table 4. 1: Sample of a list of themes with related descriptions and examples.....	115
Table 5. 1: Demographic characteristics of service user (SU) participants...	119
Table 5. 2: Demographic characteristics of caregiver participants.....	120
Table 5. 3: Demographic characteristics of Staff Nurse participants	123

## List of figures

Figure 1. 1: Overview of ecological model for health promotion.....	8
Figure 1. 2: Eight rungs of a ladder of citizen participation- Adapted from Arnstein (1969).....	13
Figure 2.1: Chart above shows the Major Ethnic Groups in Ghana. ....	38
Figure 2.2: Ghana map indicating the 16 administrative regions (also showing Greater Accra).....	40
Figure 4. 1: Stages of recruiting participants.....	92
Figure 4. 2: Researcher's adaptation of Smith et al (2012) IPA data analysis .....	112
Figure 6. 1 Showing the support tree .....	162

**List of Abbreviations:**

AMI	Any mental illness
CEO:	Chief Executive Officer
CHPS	Community-based Health Planning Services
DSM-V	Diagnostic Statistical Manual of Mental Disorders version 5
EE	Expressed emotion.
GHSERC	Ghana Health Service Ethical Review Committee
GSS	Ghana Statistical Service
ICD-11	International Classification of Diseases version 11
IPA	Interpretative Phenomenological Approach
IHME	Institute for Health Metrics and Evaluation
ISSER	Institute of Statistical, Social and Economic Research
MDs	Mental disorders
MHAPP	Mental Health and Poverty
NHIS	National Health Insurance Scheme
n.d	No date
PE	Psychotic experiences
QoL	Quality of life
SHG	Self-help groups
SMI	Severe Mental Illness
SSG	Semi-structured guide
SU	Service User(s)
TMP	Traditional Medicine Practitioner(s)
WHO	World Health Organisation

**Glossary:**

Trotro	Local commercial vehicles (such as buses and minibuses) for commuting within the cities.
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# CHAPTER ONE: BACKGROUND

## 1.1: Introduction

This chapter offers the background of the study, laying the foundation for comprehending the research problem and its significance. It provides an overview of the key issues, concepts, and context that led to the development of the present study, highlighting the relevance and importance of the research.

Following the completion and publication of the Mental Health and Poverty Project report (MHAPP, 2010), there was a shift in the provision of mental health services in Ghana; from hospital-based to community-based services. The report identified inadequate resources as obstructing community mental health service delivery and improvement. Integrating services into Ghana's community-based mental health care, like other African countries, provides significant advantages for people diagnosed with schizophrenia to be socially functioning, but such an approach comes with some challenges (Botha *et al.*, 2008).

The Government of Ghana is the leading financier for the country's mental health service. However, due to inadequate funding for mental health services, the state funding is subsidised to a smaller degree by internally generated funds and donations (Roberts *et al.*, 2014). Inadequate funding has a lot of implications for the mental health service in Ghana. The majority of people who need the support of mental health services look elsewhere, such as traditional healers and other faith-based sanctuaries for treatment because of the high cost of psychiatric medication (Ofori-Atta *et al.*, 2010; Ae-Ngebisi *et al.*, 2010).

It is estimated that 2.4 million people in Ghana live with a form of mental illness, and only 67,780 (representing, 2.8%) received treatment in 2011 (Ministry of Health, MoH, 2011). Over 97% of the mental health patient population could not access such services and, therefore, they are likely to be living with mental illnesses within the communities. The poor service delivery is largely accounted for by inadequate funding support from the government. In a comparative report in 2010, the ring-fenced Ghana's Mental Health budget in 2007-2008 was \$17,412,263 and constituted 3.9% of the total national health budget (Raja *et al.*, 2010). Roberts *et al.* (2014) reported that in 2011, Ghana's mental health service received only 1.4% of the overall national health budget and a large proportion of the allocation was spent on the provision of services for people who live in urban areas. Roberts *et al.* (2014) further indicated that the government spent more than the ringfenced budget.

The argument on funding raised by Roberts *et al.* (2014) depicts a disparity in the provision of mental health care services between people living in rural and urban areas in Ghana. The significant numbers of people living in rural areas have little access to mental health service delivery and may largely account for the increasing number of cases of mental illness within rural communities.

It can be observed that a significant portion of the mental health budget was allocated to urban areas, primarily because the three state hospitals dedicated to treating mental disorders are situated in urban locations such as Accra, Cape Coast, and Pantang. As these hospitals account for a considerable amount of government funding, it is understandable that they receive a large portion of the budget allocation (Roberts *et al.*, 2014).

Importantly, government-led mental health support systems rely heavily on community mental health care services, which operate on weekdays in conjunction with state-owned public mental hospitals. These services, typically localized, play a crucial role in complementing the broader mental health infrastructure by providing care beyond hospital settings and directly to the communities they serve. These community mental health care services, run by the government, are available on weekdays to provide ongoing support, therapy, or intervention for individuals with various mental health conditions (Roberts *et al.*, 2014). Unlike public mental hospitals that offer inpatient care, these services focus on outpatient care and provide essential mental health support during regular working hours.

As a state-run service, community mental healthcare is provided across the country and through the administrative regional branches. However, the functions of the community mental health service are limited to nurses' roles such as visitation to the service users for administration of depot injections and educational talks to promote mental health. Such educational talks include discussions with groups such as churches, television and radio programmes. These programmes have the potential to enhance community engagement and education, by promoting mental health awareness and reducing stigma (Duncan *et al.*, 2021). By offering support within familiar environments, individuals may feel more at ease in seeking help, which can foster a sense of belonging and reduce the isolation that is often associated with mental health challenges.

By embedding mental health care within the community, individuals facing mental health challenges can seek support without the need for hospitalization. The emphasis on weekdays

ensures consistent, routine-based care that aligns with individuals' daily lives and responsibilities (Castillo et al., 2019).

The Mental Health Service in Ghana strives to enhance healthcare provision for Ghanaians but faces challenges due to inadequate resources including staffing. The Ministry of Health's 2011 report expressed concern over the scarcity of mental health facilities and advocated for improvements to prevent a surge in mental health cases (Ministry of Health [MoH], 2011). Prior to MHO (2011), Ofori-Atta et al., (2010) asserted that Ghana's mental health situation was below the expected standard.

## **1.2: Challenges to Community Mental Health services**

While it is widely acknowledged that inadequate medicine management can have long-term negative effects on service users, the impact of medication unavailability on the wider population has not been fully explored. When a service user experiences a relapse due to limited resources including medication (Deng et al., 2022), not only do they struggle alone but those around them are also affected by their condition. This highlights the far-reaching consequences of medication unavailability in managing service users' conditions.

According to Oppong et al. (2016) and Antwi-Bekoe et al. (2009), there is a shortage of antipsychotic medications in the mental hospitals in Ghana. Where service users and their families cannot access the medication, there is the fear that the person experiencing mental health issues could cause harm to others and themselves.

The value of antipsychotic medications in providing relief for individuals receiving mental health services is immeasurable, especially during the acute phase of their illness. Whether a new service user is undergoing a mental disorder for the first time or a person with long-term experiences with mental illness, service users rely on their antipsychotic medications to mitigate the distressing symptoms of their condition. The utilisation of these medications is of utmost importance. Insufficient supply of antipsychotic medication can result in a concerning under-dosing of service users, which goes against the principles of proper medication management (Grissinger, 2010; Shepherd, 2020). Consequently, the challenge of managing service users in the under-resourced national mental health service becomes a significant issue for the health and wellbeing of Ghana's citizens.

In 2015, Ghana suffered a major loss when one of the largest central pharmaceutical stores in West Africa was mysteriously burnt down. The store contained a vast array of imported medications, including those donated by international medical donors like Global Fund, which

alone lost \$27 million worth of medical supplies (Lartey, 2019). An investigation into the causes of the arson revealed that corruption and inefficiencies were among the major contributing factors (Owusu-Sekyere, Adjuik and Wedam, 2017). Failure to supply medication to the regional centres and to the various hospital pharmacies created inadequate or complete shortage of medication in the many health centres. Since the medication supply chain did not deliver their promise, families and their service users struggled to access the relevant medication at the right time.

According to the World Bank (1997) and Wei (1999), corruption involves misusing public office for personal gain. In Ghana, the central pharmaceutical store was hit by a fire outbreak that destroyed crucial evidence that could have exposed corrupt practices. Unfortunately, the lack of evidence made it impossible to prosecute the culprits involved in the corrupt activities (Owusu-Sekyere et al., 2017). The alleged staged fire that destroyed the central stores had a detrimental effect on the treatment of mental illness in the country. For example, this medication shortage led to an increase in medication prices. The frontline mental health nurses' attempts to provide quality care were met with frustration, as the necessary treatment was unavailable to those who needed it. The lack of medication and medical supplies was identified as one of the reasons behind the nurses' sit-down strike (Daily Graphic, 2017).

The situation led to a decline in the mental health of inpatient service users. Additionally, nurses expressed concerns over their safety in a resource-constrained workplace. It was reported that the situation led to an increase in aggressive behaviour perpetrated by some service users towards staff members and other service users (Daily Graphic, 2017). As stated by this report, hospital staff are often assaulted by service users due to the unavailability of essential antipsychotic medications required for managing mental disorders. Botha et al. (2008) argue that discharging a service user, who has not recovered fully from an inpatient mental health facility to the family is rife in Africa. In some mental health inpatient facilities, the practice of short-term admission in the community inpatient services indicates that families are burdened with their mentally ill relatives with inadequate support (Botha et al., 2008). In addition to the inadequate support, another key burden is the lack of respite care for the caregivers.

The shortage of essential antipsychotic medications in the mental health facilities partly imply that service users may not receive the right dose of medication, under-dosing, in addition to not being medicated at all. Therefore, poor antipsychotic medication concordance is partly associated with relapse which makes the symptoms and signs of the schizophrenia worse. It is difficult to assess data on non-concordance of antipsychotic medication among the community mental health service users in Ghana.

Another challenge facing the nation's mental health service is the reduction in inpatient beds. Inpatient beds in Ghana keep decreasing in numbers (Roberts et al., 2014; Ministry of Health, 2020). Roberts et al. (2014) further explained that the inability to replace broken beds was due mainly to lack of funds. Arguably, far too many service users may be discharged too quickly. Roberts et al. (2014) provide an overview of Ghana's mental health system. According to their findings, the average length of stay for mental health service users in Ghana's three state mental hospitals is approximately 23 days. In seven general hospitals that offer admission for mental health problems, the average length of stay is around 16 days. Additionally, there are four residential community units where individuals can stay for an extended period of time throughout the year. Roberts et al. (2013) further inform that the data for length of admission to a mental hospital are drawn from one mental state hospital, thereby indicating the difficulty to obtain relevant data from these hospitals.

### **1.3 Statement of Objective**

The mental health of a population is central to all health needs. However, in Ghana, attention given to communicable diseases and other physical health conditions is far more than what is given to mental health. The mental healthcare in the country remains neglected compared to physical health.

The situation compels families to be more involved in the mental healthcare service to augment the provision of mental healthcare. Family involvement helps to improve the service user's prognosis. However, the families are burdened with the care of their service users with little support from the mental healthcare service. Considering people diagnosed with schizophrenia and their family, the situation is no different. This raises a query about whether there is a policy for the Mental Health Services to ensure both the people diagnosed with the condition and their families are well supported. An assessment of mental health policies in Ghana indicates that the country lacks policy on social support (Faydi *et al.*, 2011). There is inadequate support for families and their relatives diagnosed with schizophrenia in low- and middle- income countries (Ngabeni and Davids, 2024).

A review of the literature shows there is little formal social support for the community service users diagnosed with schizophrenia and their caregivers in Ghana's mental health system (Faydi et al., 2011). The paucity of evidence on support for the service users and their caregivers requires some attention. Essentially, there is a gap in knowledge on the support the mental healthcare services in Ghana provide for service users diagnosed with schizophrenia in the community and their caregivers. Thus, the current study seeks to investigate the support that the mental healthcare services provide for service users

diagnosed with schizophrenia in the community and their caregivers. This is aided with the use of the conceptual framework of the ecological model for health promotion (EMHP) as proposed by McLeroy *et al.*, 1988) and referred to in Section 1.5.

To improve the care of people diagnosed with schizophrenia and their caregivers, attention must be paid to their wellbeing and life circumstances in designing support services that will help them to live optimally (Galuppi *et al.*, 2010). To improve mental health services in Ghana, the development of social infrastructure is essential. According to Choguill (1999), sustainable communities require robust social infrastructure, including educational and health facilities. This infrastructure can help support discharged service users in their homes, enabling them to live well in their community where their health needs can be appropriately met. The difficulty in accessing a health facility where there is scarcity of relevant resources including medication implies that families are burdened with little support. Choguill (1999) asserts that measures that prove beneficial for an individual should also benefit society, particularly those in low- and middle- income countries. It is imperative to explore avenues that enhance and sustain mental health services for individuals diagnosed with schizophrenia and their loved ones in Ghana.

#### **1.4: Research Aim and Objectives**

In light of the discussion around the conceptual framework for this study (see Section 1.5), the central research question has evolved: How are the service users diagnosed with schizophrenia and their families supported by the community mental health services in Ghana?

##### **1.4.1: Research Aim**

The aim of this study is to explore support given to people diagnosed with schizophrenia and their caregivers living in Ghana. The participant group is not homogeneous because of it being multilingual with different socio-economic backgrounds. Participants come from different tribal groups in Ghana and have their respective languages such as Akan or Twi, Dagbani, Ewe, Ga and Hausa. All participants in this study from the Akan ethnic group could speak Twi either as their first language and English as their second language. Participants from non-Akan ethnic groups could speak their own ethnic languages with Twi and/or English as their second language. For such individuals, they considered English as another second language of choice because it is the main medium of instruction in the Ghanaian education institutions. The study projects the significance of understanding and recording the experiences of the individuals with the diagnosis of schizophrenia, their caregivers and the community mental health nurses

who offer care to the service users within the research location in Ghana. Prioritising mental health is essential for everyone, yet discussions often centre around mental ill health. Raising constructive conversations about mental health support for individuals diagnosed with schizophrenia, their caregivers and the professional community mental health nurses in Ghana can provide a direction for improving mental health service in the country.

Understanding and explaining support from the participants' perspectives is important to this study. This study captures the participants' viewpoints to reveal the parts that can guide ways of enhancing service delivery. The participants have their own experiences and may want more input in addressing their needs rather than having things done to them. Through the participants' narratives, their experiences are learnt and considered in making recommendations for improving community mental healthcare in Ghana.

#### **1.4.2: Research Objectives**

In pursuit of the research aim, the objectives listed below were pursued to answer the primary research question:

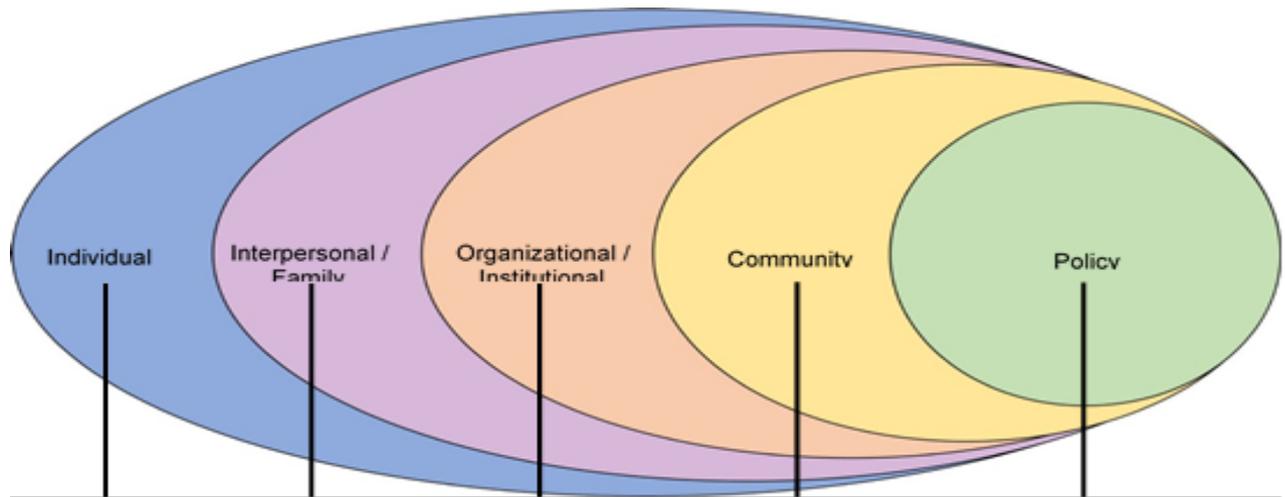
1. To investigate support for people diagnosed with schizophrenia from the perspectives of individuals with the diagnosis, their caregivers, and the professional nurses.
2. To examine the nature of support community service users receive from the community mental health services.
3. To investigate the nurses' experience of caregiving in the community settings.
4. To investigate the services that the caregivers of community service users are currently receiving and to establish what they consider to be appropriate support in the community.
5. To make recommendations concerning policy planning and implementation to enhance the provision of community mental healthcare services in Ghana.

#### **1.5: Conceptual Framework and Community mental health services**

A conceptual framework explains graphically or in a narrative form the important parts to be studied, such as the elements, constructs or variables- and the considered relations between them (Robson, 2024).

This study uses an adapted conceptual framework of the ecological model for health promotion (EMHP) (McLeroy *et al.*, 1988). The EMHP examines how individual and social

factors can impact mental health, in this case, community mental health care. It does this by examining individual service users' and caregivers' circumstances and their support needs. The EMHP is made up of five spheres, these are individual, interpersonal, organizational, community and policy, which support and maintain healthy behaviours (McLeroy *et al.*, 1988) see Figure 1 as adapted from McLeroy *et al.*, (1988) by Castillo et al (2019).



<ul style="list-style-type: none"> <li>• Increase access to mental health services and evidence-based treatments (outreach)</li> <li>• Increase acceptability of mental services (e.g., peers, community health workers)</li> </ul>	<ul style="list-style-type: none"> <li>• Psychoeducation for families to increase mental health literacy, reduce stigma, increase mental health help-seeking</li> <li>• Psychoeducation and skills training with families to reduce risky behaviors (e.g., child abuse, intimate partner violence) with mental health consequences</li> <li>• Case management and system navigation for at-risk families</li> </ul>	<ul style="list-style-type: none"> <li>• Embed mental health services within community locations (e.g., jails, workplaces)</li> <li>• Enlist trusted community locations and leaders to promote mental health</li> <li>• Change program level processes to increase mental health referrals, screenings, treatment</li> <li>• Change institutional policies to facilitate access to mental health services (e.g., school policies) and prioritize emotional and social well-being</li> </ul>	<ul style="list-style-type: none"> <li>• Activate multisector coalitions in the planning and implementation of mental health services and research</li> <li>• Activate community leaders to reduce public stigma and promote shared accountability for mental health</li> <li>• Enhance knowledge, attitudes, and collective efficacy in mental health</li> </ul>	<ul style="list-style-type: none"> <li>• Create financial incentives to encourage formation of multi-sector partnerships</li> <li>• Develop quality metrics that incorporate social determinants of health</li> <li>• Provide financial and technical support for community-based organizations to partner with the healthcare sector</li> </ul>
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Figure 1. 1: Overview of ecological model for health promotion (McLeroy *et al.*, (1988) adapted from Castillo *et al.*, 2019)

A brief discussion of the five elements will aid understanding of the importance of the EMPH in this study, specifically as it relates to mental health service provision in Ghana.

1. **Individual:** this refers to the intrapersonal characteristics such as knowledge, attitudes, self-concept and skills.
2. **Interpersonal:** refers to connecting with others within one's community. This includes formal and informal social networks and support system
3. **Organizational:** may also be known as institutional and relates to formal and informal rules and regulations for service operation.
4. **Community:** relates to formal and informal interagency working; multiagency relationships.
5. **Policy:** relates to national laws and policies. This includes the Mental Health laws such as National Redemption Council Decree (NRCD) 30 (1972) and Act 846 (2012) among others in Ghana,

The above five elements noted are, therefore, applied as a conceptual framework in the exploration of the support people diagnosed with schizophrenia living in the community and their caregivers received in the Ghanaian context. More services and activities under the EMHP framework are also presented under Figure 1.1.

The EMHP facilitates the achievement of the aim of this study. The EMHP is situated within the social context of human interactions. Thus, a study such as this, concerned with providing care within society and with specific institutions, calls for a perspective that includes phenomenological and a functionalist approach (Ocasio, 2023; Bilton *et al.*, 1981). The former (phenomenological) approach alludes to actions which take place in continuous practical knowledge of how things are done. Human actions would consider social assumptions of how things work. The actions are interpreted to be meaningful within a social context when our actions are interpreted by others as socially significant. From the latter (functionalist) approach, our institutions exist to provide services that promote the health of the society. Ocasio & Gai (2020) emphasise that the researcher must specify the institution under study. The current study identifies the community mental health services in Ghana as the institution under investigation. The Ghana community mental healthcare services must serve the mental health needs of their clientele to make itself a relevant institution for people and the catchment; hence, the society.

The approaches offer a perspective that presents mutual assistance in working towards a common goal for the provision of mental health and related services in Ghana. Enabling such cooperation requires demonstration of social support. The contribution of both formal and informal institutions within the caregiving process allows for effective integration of the mental health service users in the community. The support at the macro level includes all resources required for helping service users in need and to minimise distress. The resources include variables such as support networks and support behaviour (Vaux, 1990). Therefore, to minimise the distress of a person, the community mental health service's effort to organise resources from both internal and external sources cannot be overemphasized. Obtaining relevant resources would help the mental health service become functional in appraising and meeting the needs of both the primary clientele (service users) and their caregivers, and this involves taking relevant actions.

A key aspect of comprehending a society is to examine its institutions. These institutions are created and shaped around common procedures that occur within the society. Human actions are driven by the need to manage their surroundings to attain a particular goal (Biddle, 1986). Consequently, any assistance provided to individuals should be purposeful and fulfil a specific need.

The EMHP is distinguished by its emphasis on achieving objectives through organised efforts. The institution's purpose is to serve as a guiding culture for humanity, with all members of the organization working intentionally to achieve the collective goals. According to this approach, specific operational imperatives must be prioritized to ensure the institution can function effectively within society and fulfil its intended purpose.

The institutional approach is built upon the pillars of its existence and function. These pillars consist of three key elements. Firstly, the approach is purpose-driven and requires the collaboration of all institutional members. Secondly, it is believed that group members are inspired to work together towards achieving the institution's goals. Lastly, the institutional concept proposes that members identify with the institution's culture, which can explain why some individuals choose to work in specific fields, such as healthcare. Those who work in the community health service are motivated by the desire to assist others.

Considering the sociological perspective of health, healthcare practice is facilitated to ensure actors provide their services towards the realisation of corporate goals as mentioned earlier. The essence is to help optimisation of health and palliation of symptoms (Dalpezzo, 2009) remain the core of healthcare provision. Facilitation of healthcare practice cannot be complete without actors applying values such as empathy and respect towards others. Moreover, the clinical healthcare staff cannot practise effectively where human social values such as caring,

compassion, competence, communication, courage and commitment (Roach, 1992; 2002) towards people who use the healthcare are lacking. Healthcare practitioners are constantly expected to be compassionate (Sellman, 2011; Schantz, 2007). The focus is turned on the relationships between change and managing it. The quest here is for enabling change methodically and preserving order. Paying attention to the existing resources of the mental health care service in a society with an extended family system is worth researching, to understand support that is required for service users, and informal and formal caregivers. The thrust here is for others to be relieved of their distress in the society.

The community mental health service must establish partnerships with various organizations and groups within its community to effectively meet the needs of its people. Local voluntary agencies and government health providers are among those who are expected to offer services that cater to the community's requirements. Moreover, the community mental health service bears the responsibility of creating and executing health programs that can adapt to the evolving needs of the population it serves. The community is composed of various social structures such as family, informal social networks, churches, voluntary associations, and neighbourhoods. These structures are crucial sources of social resources and identity, and they play a significant role in shaping the social fabric of a community. McLeroy *et al.* (1988) make references to these social groups as the repositories of community "*norms and values, individuals' beliefs and attitudes.*" (McLeroy et al., 1988: p.363). By fostering a social network, these groups encourage individuals to connect with the wider community and participate in health programs that benefit both the individual and the group. Embracing a community-based approach enables us to reach a broader audience and align our operations with our vision statement, making it essential for institutions to expand their reach.

The figure above depicts services that can be provided in community settings which include multi-agency working. The collaborative working of the various agencies depicted in the diagram helps in the promotion of mental health services, strengthening and improving knowledge, views and community understanding of mental health issues, and promote accessibility to mental health services (McLeroy et al., 1988). The ethos of community service in this sense is to ensure mental health service is more accessible to the localities so that help can be available for their use.

In furtherance of McLeroy *et al.* (1988), the community mental health institutions have the power to identify health related problems and find the resources – e.g. funding, staffing with specialist knowledge and skills, other relevant materials, and official and unofficial approvals - for improving service provision. The health institutions are to ensure their operations are geared towards increasing access to mental health for the individuals and their families.

Therefore, the community service must ensure they formulate policies and provide services that epitomize their nature as a service providing for the community.

In McLeroy *et al.* (1988), the less powerful in the community include the economically disadvantaged, the unemployed or the underemployed, the homeless, disabled people, and people with stigmatising health conditions such as mental illness. The society treats such groups with contempt. They are considered unreachable - because of the severity of their conditions they are unable to engage in community activities. Their social isolation and lack of political influence means that they become the focus of services and programs. However, their non-involvement in designing services and programmes makes it difficult to identify and meet their basic needs. The services are purported to serve the needs of the people, but the core of their needs may be ignored and, therefore, makes the institutions (services) less able to serve the needs of the defined group. Supporting people in any situation must include identification of their problems and serve to ensure solutions are programmed into the institution's mandate to serve the people.

Promoting the health of the individuals and the groups within the community necessarily include increasing access for the less privileged within the community to serve on the programme designing boards. This must not be approached with a tokenistic attitude but with a serious positive attitude to ensure the concerns of the disadvantaged members of the community are addressed. In addressing this, the less privileged identified in the society must be given enough power to "make the target institutions responsive to their views, aspirations, and needs" (Arnstein, 1969).

To aid the understanding of the position of service users and caregivers in Ghana in relation to the provision of mental healthcare, the ladder of citizen participation is used - see Figure 2, as adapted from Arnstein (1969). Service users and caregivers occupy the third rung (Informing).

8. Citizen control
7. Delegated power
6. Partnership
5. Placation
4. Consultation
3. Informing
2. Therapy
1. Manipulation

Figure 1. 2: Eight rungs of a ladder of citizen participation- Adapted from Arnstein (1969)

The ladder has eight rungs which define the various kinds of citizen participation in our society. Arnstein identifies two groups of people in society, namely, power holders and citizens. Arnstein's use of 'citizen' refers to the people who wield less power in society and the 'power holders' as the phrase stands for. The concept of ladder of citizen participation defines features of participation and nonparticipation in the exercise of power within the social system.

The rungs, from the bottom to the top, are Manipulation, Therapy, Informing, Consultation, Placation, Partnership, Delegated Power and Citizen Control. The paragraph below highlights the nature of power inherent in the rungs. Manipulation and Therapy as level 1 and 2 respectively which are the two levels of non-participation. With regards to therapy, Arnstein (1969) says that this means 'participation is good for you' which in many ways is depicted by the simple application of this theory and that it requires information, which is obtainable from the caregiver. For manipulation, Arnstein (1969) explains that service users and caregivers think that they participate but in actual fact are just being used for information retrieval. The people who find themselves in this group have little influence in society. The power holders use these levels to force education or curative measures on the people. They get things done to them, and this reflects their subjection to the influences of the power holders. Next set of rungs are Informing, Consultation and Placation as level 3, 4 and 5 in order. Informing and consultation are deemed tokenistic. The process of informing and consulting is often regarded

as tokenistic because although the less powerful can voice their opinions, they often lack the resources to bring about real change. Placation is seen as part of this tokenism, where the less privileged (caregivers and service users) have less influence in making decisions to impact the health needs. The final decision rests with the clinicians who are deemed the main decision makers by virtue of their professional knowledge. It is advocated that, the active integration of family into the service user's treatment and recovery process can be a cornerstone of mental healthcare policies, and it is therefore argued that this is due to the exclusion, disempowerment, and marginalisation of families by governments (Martin et al., 2017). To redress caregiver and service user invisibility, the mental healthcare services must provide them with the relevant knowledge and skills as support to encourage full participation in policy design. Valentini et al (2016) assert that interventions aimed at providing support to caregivers have a beneficial impact on the psychological well-being of both family members and users, resulting in a reduction of the care burden. They advocate for the integration of these interventions into mental healthcare services.

The last three rungs of the ladder are where less privileged groups have the degree of power to contribute towards planning, formulation and implementation of policies. For example, the sixth rung is Partnership and the people can actively engage with power holders in making decisions to manage the services. The people are appointed to serve in various capacities in the existing structures that govern society. They can bargain for the issues that need prioritising and resource allocation. This is the level where the less powerful people in society are able to negotiate for their needs. The seventh rung is the Delegated Power where the less powerful people are given positions to play dominant roles in identified programmes through negotiations with the power holders. The eighth level is the last run called Citizen Control, where the less powerful ultimately occupy full managerial power. They dictate programmes and have full participation in them. The eighth rung is hard to attain. The perceived ultimate rung is not easily attainable by the less powerful in society. However, it is an indication for society to strive to attain the best possible goals for its citizenry.

As a social institution with a clear mandate, the healthcare service is committed to providing equitable care to all its clients. Its primary goal is to enhance the health outcomes of the population by identifying and addressing their diverse needs. The healthcare staff's primary responsibility is to meet the community's healthcare needs (Roberts et al., (2023). The healthcare service must effectively gather and utilise resources, including pharmaceutical products and information, to enhance the wellbeing of the population. By doing so, the service becomes more relevant to the community and better meets the needs of its target group. Staff members are expected to consistently deliver high-quality services to users of the service.

Seeking to provide intervention in the wider community requires the formation of partnerships with multi-agencies, cooperating with others to enhance the safety of the public. Different agencies play certain specialized roles in the community and therefore provide leadership in their areas of specialty. Cooperating with individuals, families and other agencies (i.e., both formal or informal) will collectively enhance the promotion of public health and safety. Both community intervention and the rungs of participation draw attention to different influences within the dynamics of working together with other agencies. Acknowledging these dynamics may offer healthcare providers the tools to formulate policies that will help work fairly and effectively with other agencies to improve the provision of mental healthcare services to individuals and their relatives. Furthermore, this will help identify limitations to one agency's capacity and seek the cooperation of others to enable them to deliver responsive services to the community they serve. It is by this approach that a health system can achieve major public health goals in the country.

#### **1.6: Motivation for the Study**

With 18 years of experience as a registered mental health nurse, I have witnessed the impact of schizophrenia on both service users and their loved ones. Throughout my career, I have provided direct patient care to individuals in a variety of settings, including medium secure units, general psychiatric inpatient units, community mental health services, and drug and alcohol services in prison settings.

Beyond my professional responsibilities, I have provided support to friends whose loved ones in Ghana were navigating various mental health challenges. During these difficult times, I offered remote assistance from the UK and soon became curious about the support services available to mental health service users in Ghana. As I delved deeper into my research, I discovered a scarcity of information on the support offered to both caregivers and community members diagnosed with mental disorders. This prompted me to investigate mental health support systems for service users and caregivers in Ghana. My approach to generating research ideas aligns with Creswell's (2009) recognition that personal experiences can shape a researcher's perspective on research. While these experiences undoubtedly influenced my thesis, I remained vigilant of potential biases, continuously evaluating literature and research methods with a critical eye. The methodology chapter elaborates on this in further detail.

In this thesis, I have utilised the first-person pronoun "I" to establish a clear and identifiable voice as the researcher or writer. This is because the parts of the study involved personal statements, reflections and opinions, which is buttressed by the (Park, 2021). This is particularly crucial for qualitative research, as it allows the reader to evaluate any potential influence, I may have had on the research findings.

The researcher positionality will be discussed in much detail later in the study.

## **1. 7: Outline of thesis chapters**

This thesis comprises a total of seven chapters, each of which plays a crucial role in the research process. The chapters not only provide a broad rationale for the study, but also establish the necessary framework for a comprehensive discussion of the research findings.

**Chapter One:** The present chapter furnishes a comprehensive introduction to the context of the study. The aim and objectives of the research are stated. In this section, I have established my identity as a researcher and presented my perspectives on the research subject. Further elaboration on my positionality is provided in the methods and methodology chapters.

**Chapter Two:** The chapter is in two parts; addressing literature and the literature search, and reviewing the existing literature on mental health and schizophrenia in general within the context of Ghana and related issues. It reviews literature on mental disorders including schizophrenia worldwide and in Ghana.

Whereas the first part describes the process of the literature search and review, the second part deals with literature on the cultural aspect of schizophrenic condition in Ghana. It further discusses mental health policy in Ghana.

**Chapter Three:** This chapter presents a detailed review of the methodology employed in the research study, where the epistemological and ontological concepts are extensively discussed. The chosen research approach is qualitative, and the Interpretative Phenomenological Analysis (IPA) is used to investigate the research aim. The rationale behind selecting these specific methods is also explained in the chapter.

**Chapter Four:** In this chapter, I delve into the practicalities of data collection. This encompasses my strategy for gaining entry to the research site and sourcing suitable participants for the study. Additionally, I outline the specific methods utilised to procure the data for analysis. This chapter specifically details the logistics of participant interviews, including where and how they were conducted, in order to gather the necessary information for my research study.

**Chapter Five:** The chapter provides data reports that are crucial to the study. It offers an analysis of the data for all the participant groups, namely, service users, caregivers and the registered mental health nurses within the study enclave. The data reporting stage reveals the findings of the study, which were further validated by academic supervisors during supervisory sessions.

**Chapter Six:** The findings are discussed in-depth. The discussion of the findings is offered with the backing of literature.

**Chapter Seven:** This chapter serves as the conclusion of the study and reflects on its findings. It provides practical recommendations for mental health policymakers and practitioners in Ghana based on the research outcomes. The strengths and limitations of this study are also presented. Additionally, the chapter highlights potential areas for future research on the topic.

### **1.8: Chapter summary**

Ghana has embarked on community mental health services as a strategy to ensure service users continue to receive care outside the mental hospitals and in their own locality. This study explores the support given to people diagnosed with schizophrenia and their caregivers living in Ghana – this research focus addresses a gap in knowledge in the current literature. The chapter discusses the aim and objectives of the study, and the conceptual framework used, community-based mental health care service provision in Ghana and the challenges. Motivation for the study is also mentioned.

The upcoming chapter will delve into the literature review and the strategies employed for the literature search that contributed to the advancement of this study.

## **CHAPTER TWO: LITERATURE REVIEW**

### **2.1: Introduction**

This chapter discusses the literature review and the literature search strategies that helped advance the present study. Thus, the chapter starts with a discussion of the literature search strategies, which accounted for the processes that allowed for the relevant literature to be identified. The second main aspect of the chapter explores the existing literature on mental health and schizophrenia in general and in the context of Ghana, and their related issues, such as supporting people diagnosed with schizophrenia living in the community and their caregivers. The literature review also looks at support systems that service users with schizophrenia and caregivers are engaged with. This is important since there is negligible literature that addresses the aim of this study, that is, the support that service users diagnosed with schizophrenia and their caregivers receive from community mental health services in Ghana. Therefore, this provided useful insights for the present study. The literature review was thus based on a systemic search of the literature and a narrative or traditional review which were aimed at identifying the relevant literature for the study (Ferrari, 2015). Although traditional or narrative reviews are not systematic in their implementation, they offer a wide overview of the topic of interest (Bettany-Saltikov & McSherry, 2024).

### **2.2: Literature search methods and processes**

This section discusses the processes involved in identifying the literature for the start, thus consequently the literature review.

#### **2.2.1: The Population, Interest and Context (PICO) framework**

In order to find relevant literature on the study topic, a literature search was conducted. Conducting a literature review is an essential component of the research process. It guarantees a rigorous, transparent, and unbiased approach to assessing existing knowledge, ultimately strengthening the validity and impact of the research study (Shamseer et al (2015). The nature of this research topic required an in-depth review of literature which was highly beneficial in highlighting knowledge gaps. Following the literature search and review process, this offered significant insights for the research topic and informed the choice of research methods for the study as well (Liberati et al 2009).

In the literature search process, the Population, Phenomena of Interest and Context (PICO) (Ansar, 2022) framework was used to clarify the inclusion and exclusion criteria which aided the development of keywords to facilitate the search in databases (Aromataris et al, 2024; Robson, 2024). Moreover, PICO can be used for asking qualitative questions, evaluating experiences, roles, and meaningfulness of a topic.

In reviewing the literature, the PICO model was adapted. The literature search and review started with the use of the PICO framework to derive the research question and for the literature search from databases. Thus, using the PICO framework, the research topic on how service users diagnosed with schizophrenia and their families are supported by the community mental health services in Ghana was transformed into searchable terms or phrases with the help of Boolean operators as indicated in Table 2.1.

**Table 2. 1: PICO framework guiding search.**

PICO framework	Phrasing of terms	Keywords	Searches
P	People diagnosed with schizophrenia	schizophrenia, schizoaffective,	Schizophrenia OR schizoaffective AND
	Caregivers	caregiv*, carers, helper, assistant	caregiv* OR carers OR helper OR assistant
I	Support	assistance, support, assist*, support*, help*, family support, friends support, faith-based support, religion-based support, traditional healing-based support	AND assist* OR support* OR help* OR family support OR friends support OR faith-based support AND
Co	Community and Ghanaian	Ghanaian, Ghana, community, not inpatient	Ghanaian OR Ghana AND community NOT inpatient OR ward-based

### 2.2.2: Eligibility: Inclusion and exclusion criteria

To enable relevant literature to be found, the eligibility criteria in Table 2.2 were used.

**Table 2. 2: Eligibility criteria**

Inclusion	Exclusion
Service users diagnosed with schizophrenia	Other mental health disorders
caregivers	Other agents
Support service users and caregivers get in the community	Support for inpatient users and their caregivers
In Ghana	Other countries
English language articles	Articles not in English language
Year range -2010 to 2020	Works outside this year range

The search from 2010 was used to identify the literature that existed before the promulgation of the Ghana Mental health Act 846 of 2012, and 2020 was adopted to check for the latest literature pertaining to the study. It is believed that this 10-year range was suitable enough to capture the changes in the area of study as shown in Table 2.2.

The eligibility criteria are made up of inclusion and exclusion parts as depicted in Table 2.2. Thus, the inclusion criteria have elements that must be met in the primary paper to ensure their inclusion for the study. The exclusion criteria contain elements that hinder addressing of the research question for their inclusion in the systematic review (Bettany-Saltikov & McSherry, 2024). Of importance, journal articles that met the inclusion criteria covered elements that answered the research question such as: service users diagnosed with schizophrenia and their caregivers; support service users and caregivers receive in the community in Ghana, and journal articles written in the English language and ranging from 2010 to 2020. Therefore, all journal articles that did not meet these criteria were excluded (See Table 2.2). In this way, the literature search systematically helped to reduce biases (Bettany-Saltikov & McSherry, 2024).

### **2.2.3: Literature searches**

The researcher was privy to the UK NHS library resources. Thus, in addition to Middlesex University's library resources, this ensured that a thorough and systematic literature search was conducted. Using the NHS data library resources, diverse searches of databases were conducted. However, the ones that returned meaningful articles were from APA PsycINFO, British Nursing Database, CINAHL, Web of Science and Medline.

The literature search was also aided by searching relevant reference lists of some of the articles retrieved from the databases. These databases are well documented for featuring articles related to mental health or psychiatric health care from a multidisciplinary perspective.

Search terms were developed through extensive reading of the literature and highlighting the key words used in published articles (Atkinson and Cipriani, 2018). It is well documented that the development of search terms is not a mere procedural step in the research process; rather, it is a strategic and foundational element that significantly influences the quality and outcome of a literature review (Atkinson and Cipriani, 2018). Effective literature searches require precision, exhaustiveness, and relevance, which can be achieved through careful crafting of search terms. To achieve this, the right keywords and Boolean operators were used to ensure a successful search strategy as indicated in Table 2.1.

Boolean operators like AND and OR were used to combine key terms. Wildcards (\*) were also used to broaden the search terms, considering different spellings and use of terms across English-speaking countries. The literature search aimed to capture the topic's historical components between 2010 and 2020.

### **2.2.4: Search results**

After conducting a systematic search of the literature, 19 out of 396 studies were included for the literature review, with three duplicated articles. It was observed that the evidence on the support for people diagnosed with schizophrenia and their caregivers in Ghana was quite diverse. Consequently, a more comprehensive narrative review was used to provide a better understanding of the topic. This led to the presentation of the literature review in this chapter allowing for detailed discussions on relevant areas.

**Table 2. 3: Database searches and returns**

<b>Database names</b>	<b>Hit returned</b>	<b>Excluded</b>	<b>Included</b>	<b>Duplicate</b>
APA PsycINFO, CINAHL and Medline	15	13	2	
British Nursing Database	92	87	4	1
Emcare	8	7	1	
PubMed central	278	265	11	2
Web of Science	3	2	1	
Embase				
<b>Total included studies</b>			<b>19</b>	

Also, other literature used in the study were sourced from snowballing searches of some of the 19 articles and also through narrative reviews (traditional) (Bettany-Saltikov & McSherry, 2024), which at times led to snowballing searches too, that is screening other the articles that were cited in the included studies Cambridge University Libraries (2024). There is no standard framework for undertaking a narrative review (Ferrari, 2015), however, the narrative review adapted the key search terms for the systemic search of the literature (see Table 2.1) in order to make it rigorous (Sukhera, 2022). Also hand search of materials in the library to supplement the electronic search strategy to help reduces biases using keywords searches (Bettany-Saltikov & McSherry, 2024). Though narrative reviews do not go by a scientific review methodology (Bettany-Saltikov & McSherry, 2024), it allows for the blending of multiple points of view from diverse perspectives.

Table 2.3 was presented to offer a pictorial representation of the databases used in searching for information for this study. Various databases were searched and provided various hits. Example, PsycINFO, CINAHL and Medline were searched as one database which provided 15 hits. The hits were reviewed, and 13 articles were excluded because they did not meet the inclusion criteria discussed in Table 2.2. Only two articles met the inclusion criteria. Similar approach was adopted for searching and reviewing the other databases, namely British Nursing Database, Emcare, PubMed Central, Web of Science and Embase as indicated in

Table 2.3. Searching and appraising the 19 articles drawn from the various databases shown in Table 2.3, the included articles were discussed in 2.3.2.

### **2.2.5: Themes derived from the Literature Search**

From the search literature, using the eligibility criteria, only one article came close to meeting the criteria, that was Ae-Ngibise et al (2015) 'The experience of caregivers of people living with serious mental disorders: a study from rural Ghana'. Therefore, the literature review was slightly expanded to include studies on *support systems for service users diagnosed with schizophrenia*, and studies on *support systems for services users with schizophrenia* and other mental health disorders and *caregivers* world over. This provided hints to guide the study.

Therefore, using the above templates, the literature review for this study was organised thematically or according to topics that explored the existing knowledge related to *supporting people diagnosed with schizophrenia* living in the community and their *caregivers*, especially from the Ghanaian context, and also globally. Thus, the literature review helped to focus the research question. It also helped identify the general trends, strengths and weaknesses or gaps in the relevant literature, building bridges between related topics or identifying central issues in a field (Robson, 2024; Laurie and Jensen, 2016). Therefore, the review analysed and critically evaluated the research methods and research results of previous works in the area of, mental health and its context in Ghana, schizophrenia and its related issues, and also looking at the situation globally, as well as related literature on supporting people diagnosed with schizophrenia living in the community and their caregivers in the context of Ghana. The study also reviewed the methodologies and methods employed in previous works which were of interest for the present research.

The literature review in this study, therefore, examines themes and topics such as general trends, strengths and weaknesses or gaps, methods, policy and legislation of mental health in Ghana, the mental health facilities and resources, schizophrenia as a disorder and its management, and finally the needs of the service users and their caregivers in existing empirical studies.

### **2.3: Literature Themes in More Depth**

This section discusses what the literature review is, and why it is needed. The section also covers the varied themes covered by the literature. In this case, by organising the literature review into themes it helps the researcher to identify what the literature covers, the gaps, strengths and weakness and the various positions taken by other researchers.

The literature covered a variety of themes. These themes were conveniently grouped under a key or main theme of headings that encompassed other related sub-themes. For example, the first main theme looked at works related to schizophrenia issues, and support given to service users and their caregivers living in Ghana. A few studies, under this key theme covered Ghana together with other countries and other mental health disorders. The second main theme entailed schizophrenia and various support inputs but not in Ghana, and the third key theme or heading covered schizophrenia and other mental health disorders, and related support systems globally.

The first main theme to emerge from the literature dealt with schizophrenia and various support inputs for service users and their caregivers in Ghana - Ae-Ngibise *et al.*'s (2015) work was a useful study as it evaluated the level of care required by caregivers of individuals living with mental disorders, which included schizophrenia. Cohen *et al.*, (2012) also provided useful input for the study as they examined Self-Help Groups (SHG) in the context of support for mental health service users by mental health services and caregivers in Ghana. This study, like the one before it, also covered a variety of mental disorders. There was also a significant examination of the role and scope of practice of community mental health workers in Ghana from the context of improving the care they provide (Agyapong *et al.*, 2015). Although this study dealt with various mental disorders, it was useful as it provided the scope of their work and some of the activities undertaken by them. This, therefore, presented a perspective on the type of support provided in the community for service users with schizophrenia, thus aiding the aim of the present study. In an international study of caregivers involving Ghana, I examined the level of burden experienced by caregivers. This study used secondary, cross-sectional analysis, together with the WHO multi-country data collection on global AGEing and adult health (SAGE) (Lambert *et al.*, 2017). Though the study was not on schizophrenia, and also covered India and Russia, a key finding was that caregivers mostly cared for service users by providing financial, social, emotional and physical support. However, caregivers received little support (Lambert *et al.*, 2017). In relation to the second key theme to emerge from the literature, i.e. a theme that dealt with schizophrenia and various support inputs but not in Ghana - this main theme covered various subthemes of mental health in general and

the support given worldwide. They observed that family functioning was linked to mental health rather than the physical. Another useful study was conducted to understand the needs of service users with schizophrenia in recovery by examining the type and level of social support and its association with quality of life among these service users in the city of Kuala Lumpur (Munikana *et al.*, 2017). They found that social support or having people to help was a vital misplaced element among people with schizophrenia who are already receiving formal mental healthcare. A study in Iran evaluated the effects of a needs-assessment-based educational programme. It noted that family psychoeducational needs assessment may lead to more improvement in service users with schizophrenia global function and quality of life, but this had no noteworthy consequence on their families' quality of life (Omranifard, *et al.*, 2014). In an overview of Expressed Emotion (EE) in schizophrenia, due to its impact on the nature of family relationships, family caregivers and service users with schizophrenia and, consequently, EE's impact on treatment, care and support provision, it was noted that psychosocial interventions such as psychoeducation, communication skills, crisis management, healthy coping strategies and pharmacotherapy helped reduce the high EE and improved treatment outcomes (Amaresha & Venkatasubramanian, 2012).

Another study sought to create a quality-of-life tool in Khmer (the Cambodian language) for service users with schizophrenia and family caregivers, and the resulting tools were deemed suitable for researchers to identify service users and caregivers' needs to improve their quality-of-life service users (Marutani *et al.*, 2020). Another study explored the obstacles to family resilience in caregivers of service users with schizophrenia and concluded that there was the need for nurses to help families to build their resilience (Fernandes *et al.*, 2021). One study that evaluated the impact of nonadherence to pharmacotherapy in service users with schizophrenia as it related to health care professionals, particularly social workers, concluded that the involvement of caregivers encouraged adherence; in addition, multidisciplinary team working may help identify obstacles to adherence and help service users overcome them (Shuler, 2014).

In terms of the third key theme to emerge from the literature, this theme covered issues on schizophrenia and other mental health disorders and related support systems worldwide. Some works under this theme examined the community perception and associated factors on the causes of schizophrenia in a district in Ethiopia (Belayneh *et al.*, 2019). In rural southern Ethiopia, a study evaluated the safety and impact of task-shared mental health care on the clinical and social outcomes of service users with severe mental illnesses (SMI), which included schizophrenia, and concluded that task-sharing safely catered for the massive treatment gap for service users (Hanlon *et al.*, 2019). It was also noted that better family functioning was achieved through improved family dynamics, integrating and involving the

family in the care of service users with schizophrenia/bipolar and schizoaffective disorders. Another study explored the experiences of family caregivers of people with mental disorders in Saudi Arabia, through examining the burdens that they faced and the coping strategies that they used. It was noted that caregivers experienced a variety of burdens, which needed a range of responses such as training on effective coping strategies, and psychological support such as counselling or group therapy (Sharif *et al.*, 2020). Furthermore, one study explored the strengths of family caregivers as they supported mentally ill service users in Potchefstroom in the North-West Province of South Africa and noted that family carers relied on external and internal strengths in supporting mentally-ill family members (Mokgothu *et al.*, 2015). The role of health workers in the provision of compassionate and respectful care has been noted (Cometto *et al.*, 2022).

A study of caregivers in Ghana revealed a significant proportion of them lacked adequate financial, emotional, physical, and personal care support (Sanuade and Boatemaa, 2015). Ae-Ngibise *et al.* (2015) also found that caregivers experienced multiple forms of burden, including financial strain, social isolation, emotional distress, depression, and limited time for other social obligations. Although caregiving responsibilities were predominantly shared among close family members, the extent of involvement varied and was often limited.

Another empirical study (Cohen *et al.* 2012) on self-help groups highlighted schizophrenia as one of the diagnoses in the research site. The study identified caregivers in some areas in northern Ghana formed self-help groups to provide mutual support. It also revealed that these caregivers were monitoring the health of their family members who were service users, while simultaneously offering support to other caregivers who were looking after their own sick relatives. The study also revealed a positive shift in the attitudes of these caregivers towards the service users within their families.

Some studies, although not directly addressing the aim of the present study, still served as a vital pointer to more literature and aided the understanding of this area of study. For example, in reviewing the literature, the work of Macleod *et al.*, (2011) provided useful insight into determining the nature of support that mental health nurses could deliver to carers of service users diagnosed with schizophrenia, thus identifying ways that could be used in community practice to reduce burden and increase knowledge, mental health and coping. Similarly, a systematic review of evidence on the economic burden of severe mental illness on primary family caregivers in sub-Saharan Africa, which also covered Ghana, provided useful understanding of the aim of this study against other mental disorders (Addo *et al.*, 2018). This was because Addo *et al.* (2018) provided a useful reference list such as the work of Ae-Ngibise

*et al.* (2015), due to highlighting the different study designs (qualitative and quantitative) and methods (semi-structured interviews and questionnaires) used in the different articles.

Thus, the literature review provided useful information of general trends or gaps in the relevant empirical sources. It helped in the choice of the research design, by helping to identify the ones that were used and not used. For example, from the literature review, cross-sectional, community-based data from the World Health Organization (WHO) World Health Survey was used by Koyanagi *et al.*, (2022), while Meng *et al.*, (2021) used a cross-sectional study, and a qualitative descriptive approach was used by Fernandes *et al.*, (2021), with an intervention cohort study carried out by Hanlon *et al.*, (2020). On other related care provisions and mental health studies, an explorative, descriptive and contextual qualitative research design was used (Mokgothu *et al.*, 2015), while a qualitative study was used by Sharif *et al.*, (2020). From the literature review, it was observed that the conceptual framework of the ecological model for health promotion (EMHP) was not used in these studies, therefore, serving as a useful tool for advancing knowledge in this area.

Another benefit of most of the above literature was that, although these studies gave some useful input, they did not focus on the support given to people diagnosed with schizophrenia and their caregivers living in Ghana, therefore opening this area up for investigation, as in the current research study.

In the next section, the chapter discusses the diagnosis of mental disorders.

## **2.4: Diagnosis of Mental Disorders**

Mental disorders, known as mental illnesses or psychiatric disorders, cover a wide range of conditions that can impact an individual's thoughts, emotions, behaviours, and overall mental health. From common disorders like anxiety and depression to more complex and severe conditions such as schizophrenia or bipolar disorder, this realm is diverse and multifaceted. Each disorder presents unique symptoms, causes, and impacts on an individual's life, affecting not only their psychological well-being but also their daily functioning, interpersonal relationships, and overall quality of life.

Psychiatric disorders can be assessed using two widely recognized diagnostic manuals, namely the Diagnostic and Statistical Manual Version (DSM) (American Psychiatric Association, 2021) and the International Classification of Diseases (ICD) (WHO, 2022b). These manuals provide a comprehensive classification system that enables clinicians to

accurately compare an individual's symptoms with established diagnostic criteria to diagnose and treat mental health conditions.

The UK National Institute of Mental Health (UK NIMH) (2024) explains that mental illnesses encompass a wide range of conditions that vary in severity, ranging from mild, moderate to severe. To classify these conditions, they are broadly categorised into two groups: Any Mental Illness (AMI) and Serious Mental Illness (SMI). Any Mental Illness includes all recognized mental illnesses, while Serious Mental Illness represents a more severe subset of AMI.

#### **2.4.1: What is not Schizophrenia?**

Other criteria highlighted in both the International Classification of Diseases 11 (ICD-11) (WHO, 2022b) and Diagnostic Statistical Manual of Mental Disorders V (DSM-V) (American Psychiatric Association, 2021), and Nordgaard et al (2008) indicate that certain conditions are excluded when diagnosis is being made. Castle and Buckley (2015) identified certain conditions to be excluded prior to the diagnosis of schizophrenia. These are schizoaffective and mood disorders with psychotic features, substance misuse and general medical condition, and pre-existing pervasive developmental disorder. The existence of these conditions prior to experiencing any of the positive symptoms of the disorder (delusion, hallucination, disorganised speech, or behaviour) would not pass the test for schizophrenia. Therefore, the official diagnosis of either schizophrenia or not is made based on the service user's specific signs and symptoms. In this light, assessment for schizophrenia requires the completion of full physical health assessment in addition to the psychiatric assessment to rule out organic psychoses, alcohol hallucinosis, schizoaffective disorder, delusional disorder, and personality disorder.

At this stage of the thesis, it is relevant to look into the schizophrenic conditions.

#### **2.4.2: What is Schizophrenia?**

Schizophrenia has existed as a mental disorder in the human community for over 100 years. The concept of the disorder was first published by Eugen Bleuler in his book *Dementia Praecox or the Group of Schizophrenias* (Galderisi et al., 2018) and this gave an exposition of the characteristics of the condition as an illness. Currently, the International Classification of Diseases 11 (ICD) (WHO, 2022b) and Diagnostic Statistical Manual of Mental Disorders V (DSM-V) (American Psychiatric Association, 2021) help in the diagnosing of mental disorders. The two international manuals, ICD 11 and DSM-V, influence the criteria for diagnosing mental disorders including schizophrenia. These authors and bodies explain schizophrenia in relation

to the presence of disordered thought demonstrated in the psychotic symptoms of hallucinations, delusions, catatonia, and/or disorganization.

Schizophrenia is identified as one of the leading causes of years lived with disability National Institute of Mental Health, 2024). It is one of the persistent illnesses that has a devastating impact on personal, social and economic facets of life (Torres-Gonzalez et al., 2014)

### **2.4.3: Prevalence of Schizophrenia Worldwide**

Schizophrenia, a mental health condition, affects approximately 24 million individuals globally, which translates to roughly 1 in 300 people (0.33%), according to data from the World Health Organization (WHO, 2022a; WHO, 2022c). However, a previous study estimated schizophrenia to affect one percent of the world's population (Millier et al., 2014).

The prevalence changes. For adult population, the rate is estimated to be 1 in 222 individuals (0.45%), as reported by the Institute for Health Metrics and Evaluation (IHME, 2021). In a "Global Burden of Disease" study, schizophrenia was rated among the top 20 diseases which pose the greatest threat to health and wellbeing in the world (IHME, 2021). IHME (2021) also identified mental disorders as a high cause of disability globally. Schizophrenia can have a significant impact on those who are affected by it. Typically, schizophrenia starts to manifest in the late teenage years or early twenties, with men tending to experience onset earlier than women (WHO, 2022a).

### **2.4.4: Causes of Schizophrenia**

There are many factors responsible for causing schizophrenia. It is noted that schizophrenia is caused by interactions between genes and many environmental factors (WHO, 2022a). The gene factor is the biological basis for explaining the cause of the illness. There is no single gene responsible for causing schizophrenia (Reveley, 2008; Cardno & Murray, 2003). Therefore, the biological factor is adduced for schizophrenia. Schizophrenia is also known to be caused by the neurochemical abnormalities and modifications in the neurotransmitters (Cardno & Murray, 2003). Dopamine is a chemical associated with making connections in the parts of the brain and responsible for enabling an individual to act appropriately in circumstances. Releasing dopamine helps the individual to be attentive. Presynaptic receptors (auto-receptors) inhibit the synthesis and move neurotransmitters to keep producing normal levels of dopamine in the synapse (Olguin et al., 2016). Dopamine binds to either postsynaptic or presynaptic dopamine receptors or both to maintain stable mental state. However, dysregulation of dopamine accounts for a mental disorder.

Some brain cells require dopamine to communicate with the brain cells linked to the brain region connected to psychosis. The dopamine associated with schizophrenia considers that the positive symptoms are linked to increased activity of the mesolimbic dopamine pathway, whilst the negative symptoms are linked to reduced activity of the meso-cortical dopamine track (Chong et al., 2016; Olguin et al., 2016).

In summary, the genes and dysregulation of dopamine activities in the brain predispose the individual to positive and negative symptoms of schizophrenia. Where dopamine is in equilibrium, the individual can maintain healthy and appropriate behaviour within their environment. However, genes are not the only factor implicated in the cause of the illness. The environment is noted to play a role in developing schizophrenia (Stilo & Murray, 2019). A range of environmental factors, including use and misuse of substances (such as cannabis, opioids, amphetamines, cocaine, hallucinogens, alcohol and sedatives) (Villines, 2023), birth and childhood development, have been implicated as providing risk factors to developing schizophrenia. The environmental factors posing risk of developing schizophrenia include birth difficulties (Froudish-Walsh et al, 2017) and childhood trauma (Morgan & Fisher, 2007; Read et al., 2005; Popovic et al., 2019)

During the period before birth, known as the antenatal period, studies have shown that expectant mothers who experience infections and suffer from nutritional deficiencies in the first and early second trimesters of pregnancy are more likely to have offspring who are at a higher risk of developing schizophrenia (Penner and Brown, 2007; Meyer et al., 2007). Maternal infections during pregnancy and the risk of developing schizophrenia in offspring have been studied extensively, the associations have not been consistently detected (Crow & Done, 1992; Tandom et al., 2008). While maternal influenza is the most frequently linked infection to an increased risk of developing schizophrenia (Mednick et al., 1988), other maternal infections such as rubella and toxoplasmosis during this period have also been associated with an increased liability for developing schizophrenia (Brown et al., 2002). Additionally, rhesus incompatibility presents as another factor that has been linked to an increased risk of schizophrenia (Reveley, 2008). Furthermore, certain environmental factors such as childhood trauma (Morgan & Fisher, 2007), have been identified as potential risks for the development of schizophrenia. Research suggests that experiencing the long-term separation or loss of a parent during childhood (prior to the age of 16) may increase the risk trauma thus, adult psychosis and schizophrenia (Popovic et al., 2019).

Studies show that adverse childhood experiences can have serious consequences on the person's mental health later in life (Croft et al., 2019; Gu et al., 2022). These studies investigated causal factors that linked early adversity to later impairments in learning,

behaviour, and both physical and mental health. The evidence suggest that many adult diseases should be viewed as developmental disorders that begin early in a person's life. It is therefore argued that continuous health inequalities associated with discrimination or maltreatment could be reduced by the alleviation of toxic stress in childhood.

Studies conducted by Tienari et al. (2004), Dalman et al. (2008), and Blonstrom et al. (2014) suggest that individuals who experienced viral central nervous system infections, such as mumps or cytomegalovirus, during childhood may have a higher risk of developing schizophrenia and nonaffective psychoses. Moreover, other infections including Aspergillus (Bettoni et al., 1984), Bacterial infections (Sørensen et al, 2009), Bartonella (Breitschwerdt et al., 2019; Lashnits et al., 2021), and Borrelia burgdorferi (Lyme disease) (Mattingley & Koola, 2015; Nagy et al, 2016) which predispose the person to schizophrenic symptoms like delusions, hallucinations and disorganised thinking. Bransfield et al., (2024) found that these infections contribute to acute and chronic mental illnesses. The type of infectious agent involved may play a role in determining the level of risk, as specific viruses tend to invade the brain parenchyma (Said & Kang, 2023). Such viral infections can contribute neurodevelopmental disorders in children include attention-deficit/hyperactivity disorder (ADHD), autism, learning disabilities, intellectual disability (also known as 'mental retardation'), conduct disorders, cerebral palsy, and impairments in vision and hearing (Koyuncu et al., 2013). Furthermore, viruses can hinder the normal maturation of the brain directly or through immune-induced moderators, such as cytokines, leading to the onset of schizophrenia (Kotsiri et al., 2023).

It is asserted that maternal influenza infection increases the risk of psychosis in offspring (Kępińska et al., 2020). Kępińska et al. (2020) explained that clinically diagnosed maternal, childhood, or adulthood infection is a pluripotent risk factor for the subsequent development of psychiatric disorders. It is also suggested that maternal infections are associated with an increased risk of mental disorder in the offspring (Lydholm et al., 2019), especially, infections during pregnancies (Kępińska et al., 2020). In addition to these factors, it is also suggested that infections in early childhood is another risk factor for schizophrenia (Debost et al., 2022).

The World Health Organisation (WHO) reports that individuals living with severe mental illnesses (SMI) in low and middle-income countries often lack social support (WHO, 2015). SMIs include conditions such as schizophrenia, schizoaffective disorder, bipolar disorder, and depression (Chan et al., 2011). Schizophrenia, specifically, is a persistent and severe mental disorder that impacts thinking, emotions, and behaviour generally across all societies, and for that matter Ghana (National Institute of Mental Health, 2024; American Psychiatric Association, 2021; WHO, 2022d). While the symptoms of schizophrenia can vary from person

to person, common experiences include delusions, hallucinations, emotional dysregulation, disorganized behaviour, and thought disorder (American Psychiatric Association, 2021; Miller et al., 2014).

Schizophrenia is therefore caused by numerous factors. Following a discussion of possible factors responsible for causing schizophrenia, it is relevant to consider treatment of the illness.

#### **2.4.5: Treatment of Schizophrenia and Psychosis**

This section discusses the pharmacological treatment of schizophrenia, a mental disorder characterized by psychosis. Antipsychotic medications are commonly prescribed to address psychosis, which is characterized by a diminished connection to reality. The main objectives of treating schizophrenia are to reduce the frequency and severity of psychotic episodes, alleviate a wide range of symptoms, and enhance functional capacity and quality of life). Treatment involves a combination of medication and various psychosocial interventions (Bruijnzeel et al., 2014). Antipsychotic medications are the primary pharmacological treatment for schizophrenia.

Those undergoing a psychotic episode may encounter delusions (misguided beliefs) or hallucinations (visual or auditory experiences that are not perceived by others). Gray (2019) argues that psychosis may be linked to illicit drug usage or a mental health disorder, consisting of schizophrenia, bipolar disorder, or severe depression (also referred to as "psychotic depression").

Medical professionals may recommend antipsychotic medications along with other medications to help alleviate symptoms related to conditions such as delirium, dementia, or other mental health issues. It is important to exercise extra caution and care when administering antipsychotic treatment to elderly patients. It is mandatory that all antipsychotic medication labels include a black-box warning that highlights the risk (Buckley and Rossi, 2011; Panagiotou et al., 2011). The use of antipsychotics in older adults with dementia can pose significant risks such as stroke and fatality (Neetha, Anila, Shabeesh et al., 2012). Therefore, these risks should be taken into consideration while prescribing antipsychotics to this service user population.

The empirical approach to antipsychotic treatment can lead to worsened symptoms, recurrence of the illness, unemployment, impaired social interactions, medical complications, heightened suicidal tendencies, and an increased likelihood of hospitalisation, resulting in extraordinary treatment expenses (Ayuso-Gutierrez & del Rio Vega, 1997; Kotzeva, et al., 2022). In the realm of clinical practice, healthcare professionals exercise a cautious approach

when prescribing antipsychotics, typically starting with a low dosage for service user safety. The practice of conducting treatment reviews is founded on the principles of service user safety and supported by evidence from studies such as Ayuso-Gutierrez et al (1997). These studies emphasise the significance of treatment reviews in ensuring effective and safe care.

According to Chokhawala and Stevens (2024), antipsychotics are categorised as either "typical" or "neuroleptics" and "atypical". These medications can be taken orally to decrease the overstimulation of mesolimbic dopaminergic neurons, or they can be given in a long-acting depot parenteral form. However, typical antipsychotics are known to have more adverse effects. To address this concern, atypical antipsychotics were developed to treat a wider range of symptoms while causing fewer side effects.

The empirical data revealed here suggests that antipsychotic medications are the primary treatment modality for individuals with schizophrenia in the mental healthcare system. However, antipsychotic alone is inadequate. Treatment involves a combination of medication and various psychosocial interventions (Bruijnzeel et al., 2014). Treatment is necessary because of the challenges that schizophrenia poses to the individual and the society. Subsequently, the following section delves into the complexities that schizophrenia poses to society.

#### **2.4.6: Challenges of schizophrenia to society**

The chronic nature and the extent of disability may predispose people with schizophrenia to struggle with social interactions and cognitive activities. Schizophrenia, a chronic and severe mental illness, can often render community service users incapable of performing everyday life activities independently. In such cases, the support of family members becomes crucial to ensure that the affected individuals receive the necessary care and assistance. According to Tew et al. (2012), social factors can have a significant impact on the mental health of individuals and either contribute to the development of mental health issues or alleviate the burden. Therefore, it is important to consider the social environment of individuals diagnosed with schizophrenia while providing them with community services.

Families play an important role in the lives of community mental health service users with schizophrenia. Sono et al. (2008) stated that the role families play in their relative with chronic mental illness improves the service user's prognosis. However, these families encounter some difficulties such as disruptions in family routines and other life difficulties. Therefore, families with a member suffering from a chronic mental disorder need mental health services to

intervene. Sono et al (2008) concluded that mental health services must consider supporting families when needed.

The shift from institutional to community-based care for people diagnosed with schizophrenia makes families important caregivers (Caqueo-Urizar et al., 2014; Panayiotopoulos et al., 2013). Problems may arise in relation to the provision of support for service users and their families. For example, the service user's demand for caregiving impacts negatively on the family's daily lives and health (Bevans & Sternberg, 2012). Shiba et al. (2016) argued that minimising informal caregiving burden will improve health outcomes for both service users and their families and enhance caregiver performance.

According to the Institute for Health Metrics and Evaluation (IHME) (2021), people live longer these days, however, as life expectancy continues to climb globally, people also spend more years living with illness and disability. In Ghana, life expectancy has risen from 40.68 years in 1950 to 64.17 years in 2020 (Macrotrends, 2020). The astronomical increase in life expectancy explains the country's increasing population. Evidence of people spending more years living with mental illness and disability in Ghana is hard to source. However, in 2012, depressive disorder was reported to be prevalent among people with dementia in Ghana (World Health Organization, 2012; 2014). A study of 301 diseases by Vos et al. (2013) found mental health problems to be one of the main causes of the overall disease burden worldwide, accounting for 21.2% of years lived with disability worldwide. According to the above authors, the predominant mental health problem worldwide is depression, followed by anxiety, schizophrenia, and bipolar disorder.

A review of qualitative research undertaken with people with mental health problems by Connell et al. (2012) showed that mental illness can have detrimental impacts on quality of life of people associated with the illness. For instance, Solanki et al (2008) noted that schizophrenia is a severe and debilitating disorder, which affects general health, functioning, autonomy, subjective wellbeing, and life satisfaction of those who suffer from it. Velthorst et al. (2010) also found that one of the problems associated with schizophrenia is a reduction in social and cognitive functioning. This view is shared by Raj et al. (2013) and Thrithalli et al. (2010) who argued that schizophrenia is a significant cause of disability which affects both cognitive and social functioning.

In the study by Torres-Gonzalez et al. (2014), the authors identified unmet needs linked to schizophrenic disorders, such as substance abuse and dual diagnosis. They argued that due to specific clinical characteristics (e.g., delusions, negative symptoms, neurocognitive dysfunction, and disorganization), individuals with schizophrenia may struggle to recognize symptoms of medical illness, communicate them to healthcare professionals, and adhere to

treatment. This may also impact their ability to attend regular medical appointments and follow prescribed medication regimens. Untreated symptoms of mental illness can lead to further challenges, such as adverse effects of medication, drug abuse, smoking, inactivity, and poor nutrition and hygiene. These challenges can increase the risk of serious medical problems, including obesity, metabolic syndrome, diabetes, cardiovascular disorders, and chronic infective disorders (Torres-Gonzalez et al., 2014). When mental health needs go unaddressed, individuals may not be able to access necessary treatment (Ngui et al., 2010). In developing countries without adequate mental health policies, resource allocation, workforce development, and economic burden can become significant issues (Ngui et al., 2010). In such situations, families may need to support their loved ones with mental illness in a community setting.

The evidence reveals that support for service users and caregivers in other parts of the world is inadequate. For example, Munikana et al (2017) argue that in Malaysia, formal social support services for service users diagnosed with severe mental illness remain inadequate, a situation is likely to be mirrored in other developing countries with similar systems. Psychiatric services in Malaysia are predominantly provided through the health service system, which is mainly hospital-based, encompassing both mental and general hospitals. Despite these limitations, there have been significant efforts to integrate the social aspects of psychiatric care. This has led to the development of community-oriented psychiatric services, aiming to provide more holistic and accessible care to individuals with severe mental illness. These community-based initiatives represent a crucial step towards improving the support system, although challenges in adequacy and implementation persist.

Research (Magliano et al., 2006) has shown that relatives of individuals with schizophrenia often experience less extended and supportive social networks, with reduced social contacts compared to the general population. This lack of social support can significantly impact their wellbeing, as it is predictive of a higher level of burden on these caregivers (Chien et al, 2007). Without adequate social support, relatives are more likely to face increased stress and challenges in managing their caregiving responsibilities, which can adversely affect their mental and emotional health. This, therefore, underscores the importance of enhancing social support systems for families of individuals with schizophrenia to alleviate their burden and improve their quality of life.

In a Chinese study, Zhang et al (2021) reported that the majority (72.7%) of family caregivers of service users with serious mental illness (SMI) experienced a diminished quality of life (QoL). The study also established a positive correlation between social support and QoL, as well as a negative correlation with care burden and feelings of loneliness. Additionally, the

findings indicate that care burden and loneliness play a mediating role in the relationship between social support and QoL. Essentially, heightened social support can alleviate the burden and sense of isolation experienced by caregivers, resulting in an overall improvement in their quality of life. These insights underscore the significance of implementing robust social support systems to bolster the wellbeing of caregivers dealing with SMI.

The mental health service teams focus primarily on managing symptoms and delivering effective care to individuals with mental health conditions. This approach prioritises the management and alleviation of symptoms associated with disorders such as schizophrenia, intending to stabilise patients and enhance their daily functioning. By emphasizing effective service delivery, these teams strive to provide high-quality care that meets the clinical needs of their patients. While symptom control is crucial, addressing the social support needs of service users would further enhance the overall effectiveness of mental healthcare, fostering a more holistic approach to mental health care (Dahlan et al, 2014; Dahlan et al, 2013a & b). It is argued that the holistic approach to community mental health care enhances the care provided for the community service user (Tan & Goh, 2022) in a bid to meet the service user needs. The needs of individuals encompass biological, psychological, and social aspects, including physical health, self-management, and social support. Treating mental disorders and providing psychosociological interventions in addition can enhance the overall health and quality of life of the service users (Lerner et al, 2020, Roh et al., 2020).

Despite receiving formal psychiatric services, individuals with schizophrenia often lack adequate social support in developing countries (Munikana et al., 2017). This is a missing component and is crucial for their overall wellbeing and recovery. While the country (Malaysia) has made strides in integrating community-oriented psychiatric services, the provision of social support remains insufficient. Enhancing social support systems is essential to complement the medical treatment provided and to improve the quality of life and outcomes for people with schizophrenia. Moreover, support designed for caregivers requires investigation. This is also the case for Ghana. Addressing this gap is vital for creating a more comprehensive and effective mental health care system.

Efforts to alleviate the challenges of schizophrenia should focus on addressing the progression of the illness and the similar support needs of both the person with schizophrenia and their caregiver. Improving interventions for schizophrenia is crucial for managing the increasing challenges over time. Therefore, identifying key stages of the illness where interventions are most important in supporting caregivers is essential (Munikana et al., 2017). These interventions can operate at different levels towards enhancing the wellbeing of the service users and their families on an individual level. Support from family and close friends plays a

pivotal role in alleviating the adverse effects of chronic mental health conditions such as schizophrenia (Munikana et al., 2017). This type of support significantly enhances individuals' wellbeing by providing emotional comfort, practical assistance, and a sense of belonging. Adequate social support helps individuals better cope with their conditions, reduces stress, and improves overall quality of life. It underscores the importance of a strong support network in the comprehensive care and recovery process for those living with chronic illness (Munikana et al., 2017).

So far, this part of the chapter has discussed the literature review method and described the search terms, strategy and process, the inclusion criteria and the themes derived from the search. In addition, it has explored what is not schizophrenia and what constitutes the illness, not forgetting the causes and treatment of the illness.

The next section will discuss the mental health context in Ghana.

## **2.5: Mental health context in Ghana**

This section discusses mental health context in Ghana. It presents a historical perspective and the trend for mental health services in general. This includes a brief overview of Ghana, mental health legislation and policy, mental health facilities, resources and financing, human resource capacity, and traditional concept of illness and treatment approaches.

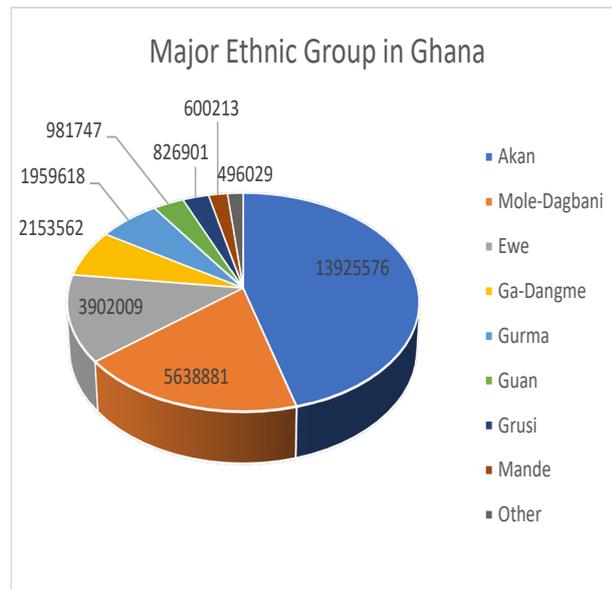
### **2.5.1: Brief Overview of Ghana**

Ghana was colonised by the British under the name Gold Coast from 1874. Ghana became the first sub-Saharan African nation to gain independence from the British colonial rule in 1957 (Owusu-Ansah, 2023). Ghana's commitment to democratic governance has since paved the way for political stability and peaceful transitions of power since the inception of the fourth republican constitution in 1992, providing an environment conducive to growth and progress.

Ghana is a sovereign and independent nation located on the western coast of the Gulf of Guinea, which lies in West Africa. The country shares its borders with Burkina Faso to the northwest and north, Togo to the east, Cote d'Ivoire to the west, and the Atlantic Ocean to the south.

It covers a land size of 238,535 square kilometres. Its population is over 32.1 million people. The official language spoken in Ghana is English, but there are also several ethnic languages spoken throughout the country. Akan is one of the nine major ethnic groups in Ghana and, as mentioned previously, it is the largest ethnic group in Ghana and constitutes 13,925,576

(45.7%) of the country's population (Ghana Statistical Service, 2018). The rest of the major groups are Mole-Dagbani, Ewe, Ga-Dangme, Gurma, Guan, Grusi, Mande and others, which refers to all foreign nationals living in Ghana. Figure 2.1 shows the population strength of each of the groups in Ghana.



**Figure 2.1:** Chart above shows the Major Ethnic Groups in Ghana.

It has a rich cultural heritage. It is home to bustling cities, rich forests, and captivating coastlines, which have witnessed the evolution of ancient civilizations to a modern bastion of stability and growth in the region.

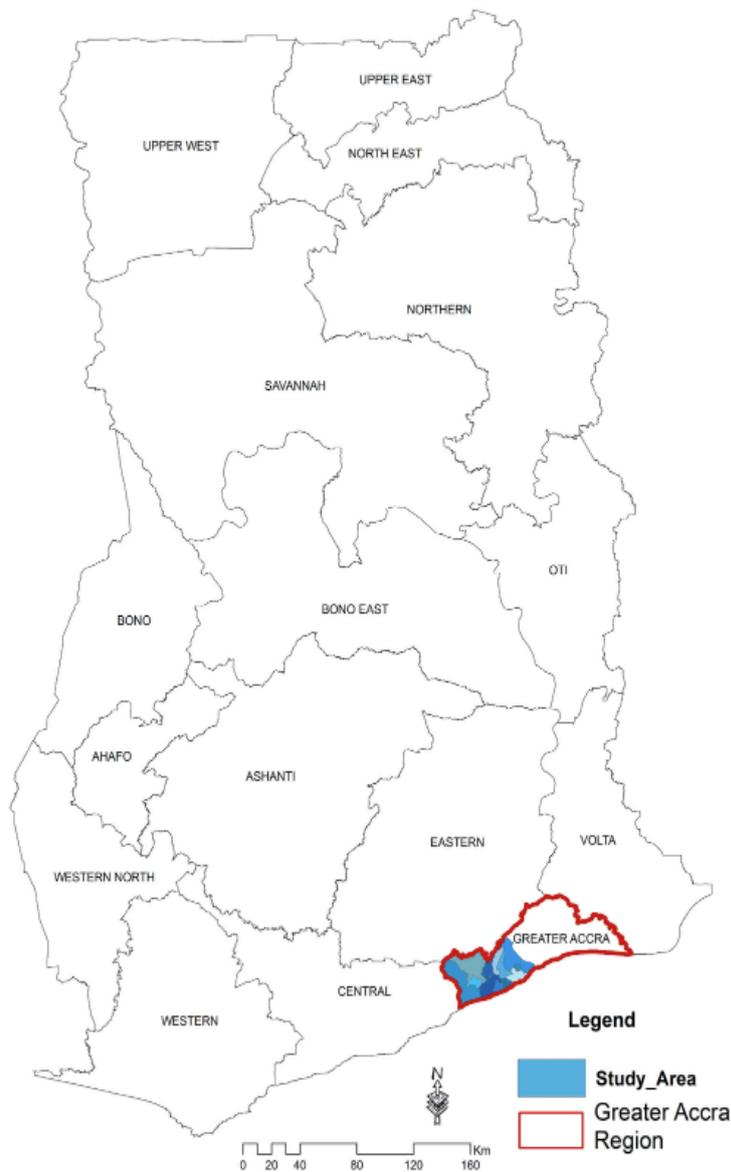
In a World Bank's report about Ghana's economy, it is noted that the country's economy has faced challenges due mainly to a mixture of domestic and global events (World Bank, 2023). These issues include the country's debt problems, slow economic growth in addition to global crisis such as post-covid crisis, the war between Russia and Ukraine and crisis in Middle East. The identified problems are likely to slow down the country's economy until 2025 (World Bank, 2023), provided revenues are managed effectively. However, in a recent national newspapers report, Ghana's economy has witnessed significant growth (Daily Graphic, 2023). Regrettably, the economy does not reflect in people's livelihoods.

The country is faced with problems such as income inequality, unemployment, and infrastructural gaps, which affect health (Amoah & Afoakwah, 2023). In a study profiling household, it is revealed that income level is one of the social determinants of health insurance uptake and service utilization (Badu et al., 2018). The situation requires effort and strategic

interventions to foster inclusive growth and opportunities for all segments of society. Intervention for these disparities is important to bring hope for the people of Ghana.

Healthcare is vital for societal development, especially in Ghana, which has faced challenges but remains committed to improving access and quality. Ghana's healthcare system, a mixture of public and private sectors, has made strides but grapples with inadequate infrastructure (Adu-Gyamfi et al., 2021), and financial barriers. The Government of Ghana has initiated the National Health Insurance Scheme (Abuosi et al, 2016) to improve utilisation of health care service. It is imperative that the government increases investment in healthcare, reforms for affordability, leveraging technology, and better disease prevention to achieve comprehensive coverage for a healthier nation (Fleming and Andersen, 1986).

A map of Ghana is shown here to help the reader see a pictorial form of the country.



**Figure 2.2:** Ghana map indicating the 16 administrative regions (also showing Greater Accra).

The shaded area (in blue) is part of the Greater Accra Region where the study was conducted. The area shaded blue is La-Nkwantanang-Madina Municipality. This is the study enclave where the community Mental Health Team is situated.

The map of Ghana shows the various administrative regions of the country. The name of each region is shown. The three main state-run mental health hospitals are in two administrative regions, namely Greater Accra (two hospitals: Accra Psychiatric Hospital and Pantang hospital) and Central Region (Ankaful Hospital).

The next section to discuss concerns the mental health policies and legislations in Ghana.

### **2.5.2: Mental Health Policy and Legislation in Ghana**

As mentioned under Section 2.3 earlier, part of British west Africa, Ghana achieved independence in 1957. It was a British colony under the name Gold Coast from 1874. Gold Coast in 1874 comprised the Fante and Ga lands which were the British Crown trading forts at the coast. These Fante and Ga lands represent a small enclave of the present-day Ghana. The British extended their rule into the hinterlands between 1900 and 1901 to include the Asante Empire as a protectorate (Fuller 2014). Long before the annexation of the Gold Coast by the British, all illnesses including mental disorders were attended entirely by the indigenous traditional healers. Where it was treated, the indigenes had a way of managing mental disorder. According to Fournier (2020), individuals with mental disorders were often overlooked or solely attended to by traditional healers. This was due to a lack of understanding among the general population regarding the symptoms and manifestations of mental illness. Fournier (2020) further noted that those who were ill were not always provided with appropriate treatment and would often be taken to traditional healers for care, as this was the common practice at the time.

The colonial government observed an increasing population of people with severe mental disorders in the streets of Gold Coast and acted by passing Prisons Ordinance in 1876 which allowed 'lunatics' to be arrested and sent to prisons (Asare, 2012). Fournier (2020) further expounds that vagrant mentally ill persons were arrested, sent to prisons, and were treated as criminals neglecting their mental health needs in confinement. In 1887, the colonial government started the first asylum at the Victoriaborg Castle in the colony in response to the realisation that the prisons were becoming overpopulated with 'lunatics'. In 1888, the colonial government enacted the Lunatic Asylum Act, as the first mental health policy, which served to legitimize the establishment of asylums and promote the creation of additional facilities (Adu-Gyamfi, 2017; Forster, 1962). As a result of this legislation, the Lunatic Asylum was constructed in 1906, providing a means to accommodate the growing number of individuals seeking mental health treatment (Adu-Gyamfi, 2017).

The subsections below discuss the other various mental health policies since colonial times.

#### **2.5.2a: Lunatic Asylum Act (1888)**

The Lunatic Asylum Act of the Gold Coast was the first Act to be promulgated in the country in 1888 by the colonial administration (Heaton, 2013). The Act (1888) legitimised the

incarceration of people suspected to have mental illness. The Act was the maiden legislation to establish the delivery of formal mental healthcare service by the colonial administration (Adu-Gyamfi, 2017). The confinement of people suspected to be mentally unwell was alien to the indigenes because before the legislation came into force, they all lived with the people with mental impairment in the community. The confinement was also deemed to have breached the rights of the service users. The families were unhappy that their service users with mental disorders were kept in confinement, and this discouraged the indigenous people from reporting their families to the authorities.

It is probable that mental disorder was perceived to be a strange disease and therefore necessitated confinement. Moreover, the perception of mental illness as a strange disease meant the service users were considered *persona non-grata* and their confinement was to ostracise them from the society (Heaton, 2013). Being ostracized from society was suggestive of mental health service users being criminalised and therefore required to be kept in institutional care.

To ensure the safety of both individuals and the public, sick individuals, particularly those with mental illnesses, were arrested and confined. This measure was taken to prevent any potential violence against them due to misunderstandings during times of crisis. In addition, confining the sick also protected the public from behaviours that may result from these mental illnesses. The Lunatic Asylum Act (1888) provided legal guidelines for detaining and treating those with mental illnesses, ensuring the safety and well-being of both patients and the public. As a result, these individuals were placed in separate care facilities and received institutional care under the supervision of trained professionals. This Act continued to be enforced for nearly a century.

Under the Lunatic Asylum Act (1888), the service was improved, and later years saw treatment and discharge of service users in their numbers. Foster (1962) describes the inpatient population of 104 in 1904, but the number declined to 80 inpatients in 1905. There were 61 males and 19 female inpatients; but 11 males and three female inpatients died. However, in 1906, the inpatient population rose to 95 but 15 male and four females died. In the same year under consideration 13 service users were discharged. Whereas 17.5% died in 1905, 1906 saw 2.6% more deaths of patients and majority were males. Again, the statistics given by Foster shows more males than females were mentally unwell. The Act did not give consideration for the care of caregivers and relatives of the service user.

The Act of 1888 was reviewed and was replaced by another mental health legislation (National Redemption Council Decree, NRCD, 30) in 1972, which was never implemented (Doku et al., 2012).

### **2.5.2b: The Mental Health Decree of 1972 (National Redemption Council Decree, NRCD 30)**

Prior to the implementation of the Mental Health Decree in 1972, the prevailing legislation was the Lunatic Asylum Act of 1888. It can be argued that the NRCD 30 replaced this Act, while retaining some of its aspects, as noted by Adu-Gyamfi (2017). Unfortunately, the NRCD 30 continued to provide institutional care, which discouraged the provision of mental healthcare in primary healthcare facilities and in the community mental health service.

Inpatient mental health services were provided in asylum facilities, however Osei et al (2011) argues that the NRCD 30 failed to protect the freedom and liberties of service users. It even encouraged unnecessary and long-term admission of people suspected to be mentally unwell, in some cases for decades. This practice of indefinite admission was a serious violation of the rights of service users and the therapeutic alliance between the service user and the treatment. The decree entrenched the confinement of people with mental disorders.

As Adu-Gyamfi (2017) argues that once a person was diagnosed with a mental disorder, they were deemed unwell enough to be denied their full rights as human beings. This made it difficult to fully implement the decree, as it encouraged the abuse of the rights and liberties of service users.

Both the NRCD 30 and the Lunatic Asylum Act of 1888 were designed to remove individuals with mental disorders from public view to reduce potential harm to the public and improve public facilities. However, the NRCD 30 offers additional protections for service users, including provisions for meeting their basic needs and preserving their dignity. Additionally, the decree permits official visitors and committees to conduct unscheduled hospital visits and interview inpatients without staff present, underscoring the government's dedication to safeguarding service users. Hospitals were also required to always ensure the safety of both service users and visitors within the premises (Mental Health decree, 1972).

Conversely, it is noted that procedures for involuntary admission in the NRCD 30 meant insufficient protection was provided against unnecessary hospitalisation and provided the opportunity for abusing the rights and freedom of service users (Osei et al, 2011; Adu-Gyamfi (2017). It may be argued that the misuse of the decree against some service users resulted in them being detained in the psychiatric institution for decades. By this decree, the service users lost their rights as persons, probably due to the public perception that they had lost their brain to the illness and could be treated anyhow. The inadequate protection of service users offered by the decree made it less famous for implementation. Unsurprisingly, the decree was not fully implemented because it discriminates against the service users it was designed to

protect. The decree was an affront to the rights of the service users, and consequently, it needed a review. Although the decree existed for 40 years, it was not fully implemented (Doku et al., 2012; Adu-Gyamfi, 2017; Walker & Osei, 2017) since it was an affront to the rights of the service users. Despite recognising that the Act required a review, it was noted that a meaningful review was made in 1990 (Ghana Law Reform Commission, 1990), but this was never enacted.

The reason for the delay in updating mental healthcare legislation can be traced back to a lack of political determination (Roberts et al., 2014). Over the years, successive governments ought to have demonstrated a commitment to supporting the Mental Health Service, but instead, their attitude towards it appeared to be one of contempt and indirect discrimination towards service users and staff. Regrettably, the decree neglected to take into account the needs of caregivers who supported service users, as the Mental Health Service was too focused on institutional care and gave little consideration to community mental health care and caregiver support. The only reform culminating into a successful enactment was started in 2003, out of which the Mental Health Law (2012) came into force in Ghana to superimpose the 1972 NRCD 30.

The next section will delve into The Mental Health Act 2012, also referred to as Act 846.

### **2.5.2c: The Mental Health Act of 2012 (Act 846)**

The Mental health Act 846 was passed in 2012 to replace the National Redemption Council Decree 30 which had outlived its usefulness. The endorsement of abuse of people's liberties under the 1972 decree was the nemesis that long called for a legislative instrument which would be consistent with the modern practices within the mental healthcare service. Although the 1972 decree was described as never implemented (Osei et al., 2011), it was also deemed as partially implemented (Doku et al., 2012). Therefore, positive action was taken towards formulating draft legislation by reviewing existing legislation and documents. This was made possible by the enormous support provided by the World Health Organisation (WHO). In the early 2000s the WHO provided specialist resource persons, financial and material resources to help the review of the existing legislation and drafting of the Mental Health Act. The draft eventually received presidential assent in May 2012 for establishing a Mental Health Board and formulating a legislative instrument which later became law in the same year (Adu-Gyamfi, 2017).

The central focus of the provisions of the Mental Health Act 2012 is ensuring improvement in providing services to people with mental illness. The Act includes the rights of persons with

mental disorders. Sections 54 and 55 stipulate the non-discriminatory treatment and basic human rights respectively. These sections allow the persons diagnosed with mental illness to enjoy all the fundamental rights as enshrined in the country's constitution. The provision also offers the opportunity for the service user to be perceived as a "person" requiring the input of the mental healthcare services. It is enshrined in section 55 that the person has the right to decent and humane treatment. The service users must be perceived first as people, citizens and active social players in their respective communities, and should be accorded all the rights befitting them. It is in this light that Walker and Osei (2017) advocate for the harmonisation of the act with the United Nations Convention of Human for the Rights of Persons with Disabilities to which Ghana is a signatory. The convention advocates for the elimination of discrimination against people with disability, creating enabling environment for the people with disability to live in the community as against incarceration - protecting people with disability against violence, exploitation and abuse. Moreover, the Act identifies the protection of vulnerable groups, namely, the aged, children and females, among others. This is a clear indication that the new Act promises protection of human rights of people with mental illness and especially, those deemed vulnerable in the society (Walker & Osei 2017).

In furtherance of safeguarding the rights of service users, the Community Mental Health Service is specifically mentioned to provide a service fit for purpose. Walker and Osei (2017) argue that the Act offers special provisions for the creation of a community-based mental health system which is modern. This bolsters decentralisation of mental healthcare service and accentuates the community mental healthcare. The Act de-emphasises institutional care to provide good grounds for the person to be cared for in their own community to ensure the maintenance of least restrictive force and continue to promote their independence (Roberts et al., 2013; Forster, 1962).

The Act gives recognition to the use of traditional medicine. It is laid down categorically in the new Act 846 that among its functions, the Mental Health Authority should collaborate with providers of unorthodox mental healthcare to optimise treatment outcomes for the person with mental illness. The acknowledgement of the traditional medicine and unorthodox approach to treating mental illness is an admission that the traditional and cultural values of the society are equally important in the quest for providing holistic mental healthcare. This approach would embrace all practitioners and would encourage unorthodox mental healthcare practitioners to collaborate with the orthodox service providers in one sense to improve understanding of mental illness and fight stigma and discrimination together. The inclusion of traditional medicine and other unorthodox practices in the treatment of mental illness recognises the traditional and cultural beliefs of the person with illness and would encourage person-centred care. For example, a Christian receiving allopathy could continue to attend church services,

engage in spiritual healing as adjunct to treatment. Further to the advantages, Act 846 directs attention to providing community mental health care (Asare, 2010). The new focus is to ensure the provision of mental healthcare is decentralised to minimise the workload on the three state-run mental institutions in Ghana.

Contrary to the positive indicators of Act 846, there is no consideration for supporting the family of the person with illness. Arguably, families and informal caregivers of the person with mental illness are left to suffer on their own till they break down, become ill and register as receiving treatment for mental illness. The puzzle that remains is who cares for the caregiver? The caregiver may resort to seeking treatment based on their belief system from unorthodox mental health provider, either an herbalist or a spiritualist for themselves or for the family suffering from mental illness.

Upon examination of mental health laws, it is evident that only Act 846 explicitly recognises the crucial role of caregivers or families. Act 846 recognizes the invaluable contribution of caregivers in supporting service users' mental health by outlining their role in appeals to the Mental Health Tribunal (as described in Section 45 of the Act). Moreover, the Act emphasises the significance of involving caregivers in developing and implementing treatment plans for service users (as stated in Section 46). Notably, the inclusion of caregivers in Act 846 is a significant step forward in ensuring that service users receive comprehensive and top-quality mental health support that acknowledges the critical role of caregivers in supporting the mental health journey of their dependant. Although Act 846 acknowledges the crucial role of caregivers in providing mental health support, none of the legislative instruments and policies offer any support for these caregivers.

The analysis of mental health legislation and policy in Ghana indicates a historical emphasis on meeting the needs of individuals seeking mental health services, with a focus on inpatient care. However, the current mental health legislation, Act 846 (2012), promotes community-based mental health care.

To furnish a thorough analysis of the mental health service in Ghana, Section 2.6 of this chapter delves into this issue.

## **2.6: Mental Health Facilities, resources, and financing**

In Ghana, mental health services play a critical role in the country's healthcare system as they offer essential resources and facilities that cater to the mental health needs of its citizens. These services provide important support treatment to individuals experiencing mental health challenges, thereby ensuring the overall wellbeing and quality of life of Ghanaians. Without

these important resources, mental health issues could go untreated in the formal healthcare system, which could lead to severe consequences for individuals and society.

The country's healthcare system has multiple tiers, including primary, secondary, and tertiary levels, with each level providing essential healthcare services. At the primary level, the healthcare system is centred around the community, sub-district, and district levels. Within the sub-districts, health care is delivered at the Community-based Health Planning and Services (CHPS) zones. The CHPS zones are the backbone of service delivery and are found at the sub-district level. Each sub-district comprises a health centre and a dedicated sub-district health management team. The district level builds on this foundation by adding district hospitals and corresponding district health management teams. This expansion ensures broader healthcare coverage and more effective coordination within the region (Ministry of Health, 2020).

### **2.6.1: Mental Health Facilities**

There are three state-run mental hospitals in Ghana. In the Gold Coast era, a mental hospital was established in urban Accra through a legislative instrument signed by Governor Sir Edward Griffiths (Forster, 1962). The hospital's first location was in the old High Court of Victoria Borg building, but it eventually became a Lunatic Asylum solely focused on custodial care (Forster, 1962), which later became the Accra Psychiatric Hospital.

#### **2.6.1a: Mental Hospitals**

There are three mental hospitals in Ghana (MoH, 2022). The state-run hospitals are Accra Psychiatric Hospital, Pantang Hospital and Ankaful Hospital.

The Accra Psychiatric Hospital holds great importance in Ghana's mental health landscape. As the first state mental hospital in the country, it was founded in 1906 to meet the increasing demand for specialized mental health care services (Ewusi-Mensah, 2001). The patients were moved to the new hospital building in 1907 from Victoria Borg due to water shortages. Since then, the hospital has been stationed at its Adabraka address in Accra. The Accra Psychiatric Hospital has remained a provider of mental health care services to the Ghanaian community.

Ankaful Psychiatric Hospital, founded in 1965, is one of the oldest psychiatric hospitals in Ghana. The Ankaful Psychiatric Hospital was established to provide specialised care and treatment for people with mental health disorders to serve Central, Western Ashanti (Asare, 2010; Ewusi-Mensah, 2001; Ankaful, 2023). Ankaful Hospital was established in response to congestion at Accra Psychiatric Hospital wards. In 1975, Pantang Hospital was established to

cater to people with mental disorders of other African descent, and it has since become a leading institution in the field of mental health care. These two public institutions, Accra Psychiatric Hospital and Pantang Hospital are located in the Greater Accra Region, while Ankafu Hospital is situated in the Central Region of Ghana. These hospitals have played a crucial role in providing mental health care services to Ghanaians for several decades.

The southern part of Ghana has all the three state mental hospitals leaving the northern part of the country without any mental hospital to manage people with severe mental disorders in the northern enclave. Moreover, apart from these two regions, the state has not built any mental hospital in the other 14 administrative regions. The current situation means that these three mental hospitals must treat people with severe mental disorders referred from other parts of the country. People referred from other parts of the country for tertiary inpatient care must travel hundreds of miles to one of these three hospitals all of which are based in two coastal administrative regions of Ghana before they can gain appropriate psychiatric hospital bed for their needs to be met.

The reasons for setting up these hospitals in the two coastal regions (Greater Accra and Central Region) are unknown. However, it may be conjectured that these two regions were chosen because of their status as housing the nation's capital city. For example, during the colonial era, circa 1844 till 1877, Cape Coast in the Central Region was the country's seat of government. The seat of government changed from Cape Coast to Accra in the Greater Accra Region from 1877 till present day (Spio, 2011). It is plausible, the teeming population and the need to improve the facilities in these two cities made it possible to establish mental hospitals to help meet the psychiatric needs of the population (Asare, 2012).

An international report on the mental health system describes the bed capacity across the community-based mental health units in Ghana was 133 per 100,000 people (WHO, 2020; MoH, 2020). The country currently has 423 outpatient mental health facilities serving the general population. However, none of these facilities are exclusively dedicated to the care of children and adolescents. According to the 2020 report, the three state-run mental hospitals in the country have a combined bed capacity of 1,171, as well as outpatient facilities and drug rehabilitation units. However, it is unclear whether the 15-bed unit for children and adolescents at Accra Psychiatric Hospital is included in this total, as the hospital's primary focus is on adult mental health care. Although specialised facilities for young people are lacking, they continue to receive treatment through the existing mental facilities. However, there is still the need for more tailored mental health services for younger populations.

While these hospitals are meant to provide refuge, they do not always prioritise service user-focused care in the low-middle income countries, as noted by Raja et al. (2021). Additionally,

the MoH report does not provide specific bed capacity information for each hospital, despite reporting an increase overall, which raises concerns about the accuracy of the reported increase.

Before the release of MoH (2020) report, the evidence available suggested that Ghana's inpatient wards were severely overcrowded. According to a study conducted by Akpalu et al. (2010) found that state-run psychiatric hospital wards were overcrowded, the average bed occupancy rate was 155%. This indicates that the hospitals were operating beyond their capacity, which could have serious implications for patient care and safety. Therefore, the provision of mental health care has been incorporated into the general health care provision across the country, a departure from over-reliance of institutional care (Doku et al., 2012). As a result, every regional hospital must now have a specialised psychiatric wing with 10 to 20 beds, ensuring that individuals at all levels of care have access to psychiatric care (Asare, 2010). The body that regulates mental health service in Ghana is the Mental Health Authority.

Ghana's allocation of mental health resources across different levels of care highlights its commitment to meeting the diverse mental health needs of its population. The establishment of these facilities at regional hospitals is a measure aimed at providing comprehensive mental health support and treatment, leading to an overall improvement in the mental well-being of Ghanaians throughout the country.

### **2.6.1b: Community Mental Health in Ghana**

The provision of community-based mental health care services in Ghana is dependent on resources such as mental health outpatient services, day treatment centres, community-based psychiatric inpatient units, and community residential facilities with trained mental health staff (MoH, 2020; Roberts et al., 2014). With the shift from inpatient mental hospitals, Roberts et al (2014) found that the majority (about 95%) of the people with mental illness including schizophrenia are treated in the community-based mental health care services. The emphasis on providing community-based mental health care means that majority of the service users, who had spent long years in one of the three state-run mental hospitals are discharged to the families. One of the principles behind the community mental healthcare centres is to support the service user to function in adult social roles as a spouse, parent, worker, or student (Drake et al., 2003). Therefore, maintaining appreciable mental wellbeing and with some degree of social functioning, but not necessarily symptom free, is a precursor of being a community mental health service user.

In addition, the community mental health care ideology is based on symptom control which emphasises that the service user is helped to remain stable in mental state and avoid hospitalisation to perform social roles well defined as recovery (SeMrau et al., 2011; Drake and Latimer, 2012, Drake et al., 2003).

For example, a study about deinstitutionalisation and community living in respect of Europe, (Mansell et al, 2012), reported that many people with serious disabling conditions now live in the community, although with substantial professional support and medication. The emphasis is on the service to consider what matters to the person with regard to their needs rather than focusing only on what is wrong with the person.

In Ghana, individuals with severe mental illnesses, such as schizophrenia, are now permitted to live in the community. Living within a supportive community that recognizes mental illness as a medical condition can offer individuals the chance to easily integrate with both clinical and social support systems (Shaw and Barker, 2004; Byas et al., 2003; Rai, Gurung, et al., 2018). Clinical support may consist of various activities, including the assessment and diagnosis of mental health conditions, prescribing medication, and monitoring both therapeutic and side effects of psychotropic medications. These medications are in short supply, which poses a significant challenge to effective mental health management in the country (Oppong et al., 2016).

The scope of community mental healthcare in Ghana is limited to nursing roles, including administering depot injections, and providing educational talks to promote mental wellness (Opare, 2013). Community mental health operates as a primary care service provider in both regional and district settings. When individuals with mental health conditions are discharged from a hospital, they require ongoing care and support in the community. Additionally, community service is responsible for promoting mental health awareness and education within the community. This includes conducting mental health assessments, providing counselling and therapy, and facilitating support groups. The community psychiatric nurses play a critical role in ensuring that patients with mental health conditions receive the necessary care and support after they leave the hospital. (MoH, 2020; Asare, 2010).

According to a report from the Ministry of Health in 2020, the country has several types of mental health facilities, including day treatment centres, community-based psychiatric inpatient units, and community residential facilities spread across the country. WHO (2022b) report notes that there are about 9,298 facilities across the country that provide outpatient mental health services at all levels, that is from primary to tertiary level across public and Christian Health Association of Ghana facilities. (WHO, 2022b).

Community mental healthcare integrates individuals with severe mental health conditions into the community, providing them with the necessary support and services to live more independently. Community psychiatric nurses play a crucial role in providing ongoing care and support. The country has a variety of mental health facilities, including day treatment centres and community-based inpatient units, which help manage mental health conditions at different levels of care.

## **2.7: Human resource Capacity in Mental Health Service**

Effective mental health services are an indispensable part of healthcare, providing much-needed care and support to those struggling with mental health issues. The presence and availability of skilled professionals in this field are crucial to ensure that service users receive top-quality care and assistance. These professionals comprise psychiatrists, psychologists, psychiatric nurses also known as mental health nurses, counsellors, and social workers. The accessibility and quality of mental health services rely on the number and distribution of these experts. Insufficient numbers of professionals can lead to long wait times, limited access to services, and a decline in the quality of care. Therefore, it is essential to allocate mental health professionals effectively to ensure timely and effective care for service users.

Evaluating Ghana's mental health system, it was found that the country's mental health staff capacity was approximately 1,889 individuals (Roberts et al., 2014; Agyapong et al., 2015; WHO, 2018). The table below displays the various staff capacities, and the data were sourced from Agyapong et al (2015) and MoH (2020).

Table 2. 4: **Professionals working in Mental Health Service in Ghana.**

<b>Professional</b>	<b>Number Agyepong et al., 2015</b>	<b>Number MoH, 2020/ </b>
Psychiatrist	12	39
Other Medical doctors	31	49
Nurses	1,256	2,463
Psychologists	19	244
Social workers	21	362
Occupational therapists	4	52
Other mental health workers	546	742
Community Mental Health Officer (CMHO)	-	561
Clinical Psychiatric Officer (CPO)	-	35
Art Therapist	-	1
<b>Total</b>	<b>1,889</b>	<b>4,548</b>

From Table 2.4 above the number of psychiatrists who were at post was 39. This means 39 psychiatrists and 2,463 nurses serve over 30 million people in the country.

Agyapong et al., (2015) reported 12 psychiatrists as being in active service. MoH (2020) indicates that 39 trained psychiatrists were in Ghana's mental health service and supported by 49 medical doctors (who are not psychiatrists). The single largest group of staff was the registered mental health nurses which almost doubled (from 1,256 to 2,463) in 2020. The 'Other mental health workers' increased by a third (from 546 to 742 members of staff) and "other mental health workers" group (561 members of staff) in Table 2.4 (MoH, 2020; Agyapong et al., 2015).

In summary, the human resource capacity within mental health services stands as a cornerstone in providing effective, compassionate, and comprehensive care to people with mental health challenges. The significance of a well-equipped and adequately trained

workforce cannot be overstated in addressing the multifaceted needs of individuals seeking mental health support. However, the funding of the services cannot be ignored, and this is discussed in Section 2.8 (impact of financial difficulties).

## **2.8: Impact of Financing Difficulties**

The financing of mental health care is a fundamental pillar in the establishment of practical, accessible, and sustainable mental health systems. Adequate funding is crucial to ensure that service users are provided the necessary care, including access to services such as therapy, medication, community support, and rehabilitation programmes. Unfortunately, mental health services in many countries are often underfunded compared to other areas of healthcare (WHO, 2021a). In low- and middle-income countries such as Ghana, there is a limited public expenditure on mental health by national governments, resulting in significant gaps in service provision and access to care. It is noted in Ghana that mental health service is 'perpetually underfunded' (ISSER, 2020). This leads to gaps in service provision, insufficient infrastructure, and limited access to care, particularly for vulnerable populations. It is relevant to identify the sources of funding mental health services in Ghana.

The sources of funding for mental health services in Ghana typically include government subventions, health insurance, private sector contributions, and international aid from other countries such as the United Kingdom's Department for International Development (ISSER, 2020).

In a global survey of methods of financing mental healthcare in 121 countries, four methods, namely, tax based (54.5%), out-of-pocket payment (38.6%), Private insurance (4.5%) and external grant (2.3%) (WHO, 2005) were identified. A recent global survey maintains out-of-pocket payment as one of the major sources contributing about half the mental health funding pot; mental health service and antipsychotic medications is 41% and 49% respectively is entirely pay-out-of-pocket payment (WHO, 2021b).

The use of direct out-of-pocket payments in health financing is regarded as a regressive approach, as it places financial burdens on individuals who can least afford care. These payments have the potential to result in impoverishment or exacerbate existing financial hardship on service users and their families (Chisholm et al., 2019).

In Ghana, the government is the main provider of mental health care services and the mental health budget is ring-fenced (Raja et al., 2010; Roberts et al., 2014). The allocation of funds is primarily directed towards hospital-based care (ISSER, 2020; WHO, 2021b), making it difficult to identify the real financial support for community mental health care. The assessment

of government expenditure on mental health in 78 countries, Rajkumar (2022) notes that the Government of Ghana, like the other low- and middle-income countries, spends less than 1% of the nation's budget on mental health services. The source of government allocation to the health budget is tax based. The government's money is insufficient, and they must deduce means of generating funds in their respective hospitals to supplement their budget allocation (Raja et al., 2010). The practical approach for the mental health service to generate extra funds is through operating costs (Raja et al., 2010). The out-of-pocket payment becomes a conscientious approach for generating funds locally in support of the mental healthcare service.

Another major source of funding is external grants. The Basic Needs (a non-governmental organisation) is on record to have provided \$651,660 to the mental healthcare services in 2007-2008, this included contributions from the United Kingdom Department for International Development, the European Commission Development Fund and a private British foundation called Comic Relief (Raja et al., 2010; ISSER, 2020).

In addition to the above, Ghana has embarked on a National Health Insurance Scheme which was first established in 2003 by the National Health Insurance Act, 2003 (Act 650). Act 650 was annulled in 2012 and substituted by a new law called Act 852 (2012). The primary objective of Act 852 is to ensure that every individual living in Ghana and non-residents visiting the country have access to universal health insurance coverage. This act is designed to offer healthcare services to all those enrolled in the scheme. This means that people who are not registered with the scheme cannot benefit from it (National Health Insurance Authority, 2018).

This limited funding impacts on the community mental health care service provision (Saraceno et al., 2007). Despite the promise of integrating mental health care into primary health care to reach a larger population, identifying the actual financial support for community mental health care remains a challenge, particularly in Ghana where mental health still struggles to gain recognition.

The mental health service faces major challenges due to a lack of adequate funding to cater to the large number of individuals diagnosed with mental health issues, particularly those with schizophrenia. This constraint hampers the work of community mental health professionals to provide the necessary care and support to those in need. Similar funding problems have created inequalities in mental healthcare provision between urban and rural population of the country. Inadequate funding also impacts on the availability of both human and material resources, such as provision of infrastructure and recruiting adequate mental health staff who are professionally trained to deliver the service. The mental health service is also constrained with inadequate psychotropic medications. These challenges, therefore, put the families who

constitute informal caregivers in a prominent role to help in the management of mental health service users diagnosed with schizophrenia in the community.

Although the sentiment in Ghana is that the mental healthcare is offered free of charge to the service user (Mental Health Act 846, 2012; Adu-Gyamfi, 2017), in practice, service users continue to pay for the services and medication. As an under-resourced service, the management has agreed on fees to pay when community service users attend hospital for psychiatric reviews and pay for their medication. This is another strain on the service user and their families. Therefore, compliance becomes a difficult issue to assess in community service users who cannot buy the medication or attend their reviews. One of the most pressing issues is that individuals who live with long-term mental illnesses, such as schizophrenia, often struggle to meet their basic needs. Those who have been unemployed for an extended period may face challenges in obtaining the necessary medications, leading to financial burdens for both the individual and their loved ones. Funding for these services is often insufficient and impacts quality service provision.

The World Health Organisation (WHO, 2005) recommended improving access and use of psychotropic medications. The availability of these medications requires investing into the healthcare system. However, the primary healthcare facilities in Ghana face limited availability of medications, leading to service users having to resort to out-of-pocket purchases from nearby pharmacies to meet their healthcare needs (MoH, 2020; ISSER, 2020). Inadequate supply of antipsychotic medicines to community mental health facilities in Ghana remains a problem (Roberts et al., 2014). The analysis of the availability of antipsychotics in the three state-run hospitals, for example, indicated that there were frequent shortages due mainly to inadequate financing of these facilities (Oppong et al., 2016). The Ghana Mental Health Service's difficulty in ensuring the availability and accessibility of psychotropic medications, at least a decade after the publication of the guidelines, demonstrates Ghana's poor performance in meeting the needs of the nation's service users and failing to meet the WHO recommendations on psychotropic medication programme. The situation raises a concern about funding community mental health services in Ghana. Quarshie et al (2021a) notes successive governments' indifferent attitudes towards mental healthcare. Such an attitude culminates in poor allocation of financial resources to mental health service and infrastructure, which increases burden of care provision.

Poor resourcing of mental health services arguably heightens the public fear of people identified with mental illness. Where service users and their families cannot cope, there is the fear that someone might commit suicide. In the world ranking of suicide death rate, Ghana's suicide rate is 2.97 (World Life Expectancy, 2017), suggesting that Ghana has few suicide

deaths. However, the Ghana Statistical Service (GSS, 2018) reports that death by suicide, violence, homicide or accident within 12 months preceding the 2010 census was 18,938 deaths. The report does not associate mental illness to suicide. Similarly, Quarshie et al (2021b) reported that more males (47.7%) than females (29.5%) committed suicide in Ghana and did not associate suicide with mental illness. The study by Quarshie et al (2021b) supports the WHO (2014a) evidence that estimates that around 800,000 deaths by suicide occur each year and 75% of these happen in the low-and-middle income countries including Ghana. Inadequate funding remains a significant challenge for improving mental healthcare in Ghana.

The next section looks at the overview of mental illness, especially schizophrenia, in Ghana. This includes examining traditional view of diagnosing mental illness, causes of and treatment approaches in the country.

## **2.9: The Mental illness in Ghana**

This section explores mental illnesses in Ghana and the cultural context of mental illness in the country.

To ensure the maintenance of population health, the United Nations launched the Sustainable Development Goals (SDG) in 2000, which are seventeen goals to provide guidance for member states to improve population health. The goals aimed to tackle poverty; hunger; encourage good health and wellbeing; quality education; gender equality; clean water and sanitation; affordable and clean energy; decent work and economic growth; industry, innovation and infrastructure; reduce inequalities; sustainable cities and communities; responsible consumption and production; climate action; life below water; life on land; peace, justice and strong institutions; and partnership for the goals (United Nations, 2024). Good health and wellbeing are a goal relevant for this thesis since it seeks to improve the mental health of people in Ghana.

The Ghana Health Service is commissioned to implement approved national policies for health delivery in the country, improve access to good quality health services, and ensure careful management of the resources available for the provision of the health services (Ghana Health Service, 2022). The country's health service comprises departments such as general health (which encompasses the physical health of the people) and mental health. As an agency under the Ministry of Health, the Mental Health Authority was established through ratification of the Mental Health Act 846 (2012). The authority is mandated by Act 846 to recommend mental health policies to the Ministry of Health for implementation; to ensure the establishment of quality mental health care accessible to all, cost-effective and culturally relevant. The current

model of mental health care minimises over-concentration of institutional care and endorses community care and integrates mental health care into general health care (Osei, 2022). Therefore, the promotion of community mental health care is to ensure care is provided to the wider population to meet the health definition which highlights the physical, mental and social wellbeing of the citizenry (Yardav, 2017).

WHO has included mental wellbeing in the definition of health as: ... a state of complete physical, mental, and social wellbeing and not merely the absence of disease or infirmity (WHO, 2001b, p.1, cited in WHO, 2005, p.2). WHO view mental health promotion as integral to public health. Public understanding of mental health issues offers an opportunity to improve the mental health outcomes in Ghana. It is therefore relevant to look at the status of schizophrenia within the Ghana mental health system as the next subheading to examine in this chapter.

### **2.9.1 Schizophrenia: Ghanaian context**

Schizophrenia is cited as one of the mental disorders in Ghana (Gyamfi et al., 2023). In Section 2.9.2c (treatment of schizophrenia), schizophrenia remains the most treated mental disorder in Ghana (WHO, 2022d). The country treats 33.21% of 59,793 people living with schizophrenia (Agyapong et al., 2015). This highlights the significant focus on managing this chronic mental disorder. The frequent treatment of schizophrenia indicates that it remains a major public health concern, demanding substantial resources and specialised care within the mental health system to ensure that the treatment gap is minimised.

The available evidence on Ghana's mental health status indicates that there are seven such disorders, namely schizophrenia, bipolar disorder, major depressive disorder, epilepsy, alcohol abuse, drug abuse, and suicide deaths (WHO, 2022d). While it is unclear why suicide deaths are categorized as a mental disorder when treatment cannot be offered to the deceased, epilepsy is considered a mental disorder and is therefore addressed through mental healthcare services despite it being a physical ailment. This could be attributed to the associated social stigma, which is similar to that observed with mental disorders. Therefore, when excluding suicide deaths and epilepsy from the list, the number of severe mental disorders comes down to five.

The prevalence of mental diagnosis in Ghana as covered by WHO (2022d) is summarised in the table below:

**Table 2. 5: Prevalence and Treatment Coverage of selected Mental Disorders.**

Diagnosis	Sex (People above >30<70 years old.)		Young adults (20-29 years old)	Older age (70+)
	Female	Male		
Schizophrenia	30,729	29,064	14,463	971
Bipolar Disorder (BD)	83,354	74,189	46,054	3,257
Major Depressive Disorder (MDD)	499,383	286,186	183,502	53,992
Alcohol Abuse (AB)	75,791	79,458	46,751	4,036
Drug Abuse (DA)	54,678	108,708	70,154	1,359
Epilepsy	64,043	66,823	24,576	4,839
Suicide Deaths	214	1,852	356	305

Source: WHO (2022d) Ghana: WHO special initiative for mental health situational assessment. Global Mental Health.

The last two disorders (epilepsy and suicide) in Table 2.5 have been discussed above. Stigma remains a significant obstacle for individuals with schizophrenia in Ghana. Misconceptions, fear, and discrimination often prevent people from seeking support in timely manner and appropriate care.

Access to mental health services is crucial for individuals needing care and support for mental health concerns. The quality of care provided depends heavily on the availability of skilled professionals, including psychiatrists, psychologists, mental health nurses, counsellors, and social workers. To ensure service users receive timely and effective care, it is vital to have an ample number of mental health professionals assigned to their needs. Where there are shortages of professionals, the people may be faced with limited access to services and reduced care quality. Therefore, proper allocation of mental health experts is critical to ensure service users and their families receive optimal care and support.

The promotion of mental health care in Ghana is under the Ghana Mental Health Authority. It is noted that the doctor-service user ratio with one psychiatrist is 1.5 million people in Ghana,

and the location of the three psychiatric hospitals are all in the southern part of the country meaning that a large proportion of the Ghanaian population do not have access to mental health care services (Adu-Gyamfi, 2017). The 2023 MoH report indicates progress in human resource development, as highlighted in Table 2.1. However, Woebong et al's (2023) study reveals inadequate mental health infrastructure and limited resources in Ghana. Awaf (2016) commented that the Chief Psychiatrist of Ghana described mental healthcare in the country as poor. Despite a surge in mental disorder cases, the treatment facilities available were insufficient to meet the growing demand. This underscores the importance of enhancing partnerships between agencies, community volunteers, traditional healers, and faith-based mental health practitioners. It is therefore relevant to discuss the cultural context of mental health care in Ghana.

### **2.9.2: The cultural context of mental health care in Ghana**

The cultural influences on mental health remain important in the Ghanaian traditional society. In this society, events are given cultural interpretation, which refers to the cogent principles held by a people in a community. Twumasi (1975) argues that the community's basic premise of thinking influences their worldview. Therefore, understanding the beliefs about illness in general and mental illness in particular is important to mental health practice, education, and advocacy (Opare-Henaku and Utsey, 2017). It provides the cultural explanation for the cause and meaning of events (Conrad & Barker, 2010). Conrad and Barker (2010) further argue that the construction of illness is inextricably linked to the management of it.

This section discusses the cultural persuasions of mental illness- schizophrenia- in Ghana.

The country's mental healthcare is known to be provided by traditional and biomedical healthcare providers. The traditional healthcare providers have existed among Ghanaians from pre-colonial era (Barimah, 2016). When people became unwell, there were certain individuals endowed with special knowledge and skills (traditional healthcare providers) in their localities who provided treatment to the sick, and similar practices have been passed from generations to date (Abdulahi, 2011) in the Ghanaian society (Amponsah et al., 2023; Barimah, 2013). The practices are extended across pregnancy and childbirth (Troskie, 1997), physical health (WHO, 2013), and mental healthcare (Gureje et al., 2015, WHO, 2013). The traditional healthcare providers vary in terms of size, from small to large treatment centres depending on the potency of treatment the practitioner offers. The practitioner gains popularity based on the effective treatment provided which is associated with having large treatment centres – these are the healthcare practices provided countrywide (Kwame, 2021; Barimah, 2013).

The nature of the traditional healthcare practices is deemed to combine the ethics of the society and its religion, and cultural values. The traditional Ghanaian believes in the adage in their local parlance that ‘the palm frond would not creak if nothing pricks it’; to wit, nothing happens by chance. Therefore, an individual’s health or illness is believed to be associated with the metaphysical or supernatural sphere (Opare-Henaku, 2013, Asamoah et al., 2014). These traditional healers are individuals endowed with the expertise to treat illnesses and are based in the community but may be supported by a few other people who run errands for them (Abdulahi, 2011; Asamoah et al., 2014; Opare-Henaku, 2013).

Ghana is described as a highly superstitious and religious country (Asamoah-Gyedu, 2013; Arias et al, 2016). Early anthropological reports (Field 1955) on Akan people’s (in Ghana) beliefs about mental illness emphasised the influence of witchcraft and curses as explanations for such conditions. Within these belief systems, mental illness is often attributed to spiritual entities seeking to cause harm or punish an individual for perceived wrongdoing. These spiritual influences are believed to manifest in unexpected and disruptive behaviours, reinforcing the notion that mental illness is rooted in supernatural causes (Khissay et al, 2017; Kpobi and Swartz, 2019). Akans share fundamental views on causality, responsibility, ethics, and social order with other Ghanaians (Gyekye, 1995).

Akan cultural beliefs influence the concept of aetiology and management of the illness. Within the Akan community, a person is composed of three main elements. They are the physical element - mortal part (“Onipadua”), personality element (“sunsum”), and intellectual element (“okra”) which is the mental acumen. In the traditional Akan group, the wellbeing of the individual is dependent on a balance of these three components (Brautigam and Osei, 1979; Sarpong, 1974). The head “tiri” contains the brain “adwene”. Some illnesses are considered as physical because they do not make the human organs function satisfactorily. In Patel’s (1995) description, illnesses affecting the “sunsum” or “okra” can be grouped under mental disorders. However, illnesses that affect the “sunsum” or “okra” are hard to diagnose and treat and are chronic.

Causation of illnesses in non-western societies is identified as ‘personalistic’ and ‘naturalistic’ (Foster, 1976; Foster and Anderson, 1978). The personalistic theory explains illness as being caused by the active, purposeful intervention of perceived agents such as human beings (sorcerers or witches), non-human beings (ancestors, evil spirits, or ghosts) and supernatural (powerful god or deities) (Foster and Anderson, 1978). These are unseen forces and act in punitive mode. The individual becomes ill as a result of punishment meted out exclusively to the sick by any of these agents. The theory, therefore, abhors the notion of one becoming ill by accident. Every cause of illness is a deliberate act of belligerence of the agent. In Akan

society where the cause of an event is unknown, they believe it is ordained by God, the gods or ancestral spirits including ghosts who are unseen forces.

The naturalistic cause of an illness is where there are imbalances to the body as a system. The cause of an illness refers to natural events within the individual's social and cultural environment.

The human factor as the causative agent refers to disobedience towards the laid down principles, which can cause an illness. This is inextricably linked to African beliefs and the cause of illness (Mbiti, 1970, Magesa, 1997, and Gyekye, 1995). Mbiti (1969) argues that the African's meaning of life events is based on their beliefs associated with the history and culture of the people. Searching for a cause of illness within the African social and cultural milieu, it is perceived that the sick has been bewitched.

Further to the witchery, Gyekye (1995) and Sarpong (1975) attribute illness as caused by breaking taboo(s). The indigenous and traditional societies have enacted norms to regulate behaviour that ensures orderliness in the society. Failure to obey the norms of society, either by omission of rightful or commission of wrongful act could result in illness, through the machination of the spiritual forces.

Society reveres and observes certain cultural norms; breaking them comes with sanctions. Sarpong (1974) submits that where individuals break a taboo wittingly or unintentionally and in secrecy, it attracts a punishment within their cultural milieu, which is carried out by the 'spiritual agent'. The punishment must be commensurate with the offence committed (Omonzejele, 2008). The punishment could be an unexplained disease/illness.

In situations where taboos are broken publicly, the public penalises the culprits. The offender in the past was banished which had psychological implications for the banished and their families. Foster (1976) commenting on non-western cultures, Aja (1999) and Akpomovie's (2014) works on African societies assert that sorcerers, witches, ghosts and ancestral spirits behave maliciously towards the victim. Similar to the trio, Sarpong (1974) argues that witchery is evil, and it is employed to make people ill in Ghana. Therefore, a person becomes ill when they are bewitched, or a spell is cast by the spirits to make the victims ill.

### **2.9.3: Traditional Approach to treating Mental Illness in Ghana**

In a sub-Saharan African country like Ghana, traditional healers play a significant role in treating mental illness (Esan et al., 2019; Oyelade & Nkosi-Mafutha, 2022). The belief that

mental disorders were caused by evil spirits, witchcraft, or unclean spirits has been prevalent in Ghanaian cultures throughout history. This perspective, rooted in spiritual, social and cultural (that is, supernatural) explanations, often links mental health issues to spiritual disturbances or divine retribution (Kpobi & Swartz, 2018; Gureje et al., 2015). These disorders are interpreted as a result of witchcraft, idol worship, or the influence of family gods on the individuals with mental illnesses (Kpobi & Swart, 2018). These spiritual explanations often dictate the treatments and responses to mental health issues. Therefore, traditional medicine practitioners (TMPs) and faith-based practitioners such as churches provide different kinds of treatment for mental illnesses (Galvin et al., 2023). The TMPs rely on culturally rooted practices such as divination, concoction, and rituals to appease the gods. These methods are deeply intertwined with the spiritual and cultural beliefs of the communities they serve, reflecting a comprehensive approach to health and wellbeing.

**2.9.3a: Concoction:** Concoction, in the context of traditional healing, refers to the physical manipulation of the body or the application of herbal mixtures (Komolafe et al., 2021; Rai et al, 2023). These methods are believed to expel harmful spirits or energies from the body. The practice is based on the belief that physical or spiritual blockages within the body can cause mental illness, and releasing or unblocking these forces is necessary for healing.

**2.9.3b: Divination:** The work of Gyekye (1995) explains that TMPs perform divination as a treatment method. The diviners give information about the cause, nature and treatment of the diseases. Although divination is a common practice used to diagnose the cause of mental illness (Esan et al., 2019), Akin-Otiko (2013) asserts that it is used as a spiritual intervention for all aspects of life including health needs. In a study by Galvin et al. (2023), the authors explore the ritual of "throwing bones" onto a mat, which Traditional Medical Practitioners (TMP) then interpret. Throwing the bones involves tossing various objects, such as animal bones, dice, shells, dominoes, and other items individually. Through divination, TMPs aim to establish communication with the spiritual realm to identify the underlying issues affecting an individual's mental health. Divination may involve interpreting signs or entering trance-like states to seek guidance from ancestral spirits or deities (Shange & Ross, 2022; Thornton, 2009, 2017). The insights gained from divination assist in determining the appropriate course of treatment.

**2.9.3c: Rituals to Appease the Gods:** Rituals are central to the traditional treatment of mental illness. These rituals are performed to appease the gods, spirits, or ancestors believed to be responsible for the mental disorder. The rituals can vary widely depending on the specific culture and belief system but generally involve offerings, prayers, chants, and ceremonies designed to restore balance and harmony between the individual and the spiritual forces. The goal is to remove the curse, heal the spiritual affliction, or regain favor with the gods, thus alleviating the mental distress.

In prayer camps, for example, *healing* is based on the concept of attaining 'God's grace.' The grace of God is perceived as the solution to a specific plea, and in the case of healing, it is the desired restoration of health. Prayers and fasting were found to be key elements of the process to seek forgiveness for wrongdoing or to obtain blessings from God to recover from a mental illness (Gyimah et al 2023). The practice of religious activities is crucial in removing the demons that are believed to cause a person's illness or suffering (Osafo et al., 2017). The spiritual leader has the authority to determine the nature and details of these interventions without involving third parties, such as caregivers or the individuals receiving the services, to prevent the potential for abuse (Osafo et al., 2017).

The enduring practice of participating in religious activities to seek healing is rooted in a deep belief in the power of divine intervention. Many individuals turn to religious practices such as prayer, worship, and participation in religious ceremonies not only as a spiritual duty, but also as a way to seek divine help for their ailments (Aghukwa, 2012; Lasebikan et al., 2012; Girma & Tesfaye, 2011; Crawford and Lipsedge, 2004). This inclination is driven by the conviction that God or a higher power can bring about healing that may not be attainable through conventional means alone.

The reliance on religious participation is deeply ingrained in culture and is also driven by an individual's desire for recovery and trust in the spiritual effectiveness of religious practices (Nyame et al., 2021; Read, 2019). For many, faith provides solace, hope, and a sense of control in the face of illness, especially when dealing with conditions like mental illness, which are often stigmatised or poorly comprehended. Therefore, recognising the tie between religion and healing underscores the importance of considering spiritual beliefs when addressing mental health needs. Integrating religious and spiritual support into healthcare, particularly in culturally diverse settings, can improve the overall wellbeing of individuals who consider their faith a crucial component of their healing process. To make treatment of mental health more comprehensive, a collaborative working relationship between faith-based or traditional and

allopathic medicine practitioners can ensure that service users receive comprehensive and culturally sensitive treatment.

The traditional methods of treating mental illness are respected in many traditional African communities. They are often the first line of treatment for mental health issues (Gureje et al., 2015; Uwakwe & Otakpor, 2014; Spagnolo & Lal, 2021), especially in areas where access to modern mental healthcare is limited. The reliance on spiritual and cultural practices underscores the importance of understanding and integrating these beliefs into broader mental health strategies in the Ghanaian society. It is noted that traditional healers offer significant psychosocial support to individuals with mental health issues, especially in the communities where formal mental health services may be limited or inaccessible. Their care is valuable not only for the treatments they provide but also for their availability, accessibility, and affordability, making them a crucial resource for many communities (Ae-Ngebise et al., 2010).

The spiritual explanations often dictate the treatments and responses to mental health issues. For instance, people believed to be possessed or cursed might undergo rituals, exorcisms, or other forms of spiritual healing rather than receiving medical or psychological care. This approach often overlooked the biological, psychological, and social factors that contribute to mental health, leading to a lack of understanding and support for those suffering from mental disorders.

**Summary:** The chapter has discussed the literature review for this study. It covered the literature search methods and the review of the relevant articles for this study. Moreover, the chapter delved into the biomedical and traditional causes of schizophrenia and their treatments. Furthermore, the concept of illness to a traditional Ghanaian was discussed, identifying causes of illness agents such as ancestral spirits, witches, and ghosts and breaking of taboos. Therefore, treatment must be based on the causative factors. It is no wonder to observe the traditional medical approaches (namely, concoction, divination and rituals to appease gods) emphasise the practices involved in each treatment approach.

It emphasises the significance of mutual understanding between biomedical model practitioners and traditional/faith-based healers in integrating these diverse health systems. By recognizing and respecting the different approaches to health and illness, both systems can collaborate to provide holistic mental health care, which ultimately enhances the overall health outcomes for individuals in Ghana. This integration requires open dialogue and cooperation to ensure that biomedical and traditional healing practices can complement each other.

In the upcoming chapter, I will delve into the methodology employed in this study. This will encompass detailing the research design, data collection methods, and analytical approaches utilised to address the research questions. A comprehensive explanation of the steps taken to ensure the study's reliability and validity will be provided, including the rationale behind the chosen methods and any ethical considerations that were taken into account.

# CHAPTER THREE: METHODOLOGY

## 3.1: Introduction

In this chapter, I will delve into the philosophical underpinnings of my study. Within the realm of research and its frameworks, two primary paradigms for comprehension prevail: the quantitative/positivist (scientific paradigm) and the qualitative/ 'interpretivism' paradigm. My focus is on the qualitative research design and the ontology and epistemology that guide my approach. Specifically, I will examine the Interpretative Phenomenological Approach (IPA) I adopted for this research. By exploring these foundational elements, I aim to gain a better understanding of the methods I employed for data collection, which I will detail further in Chapter Four.

## 3.2: Qualitative Research Design

Qualitative research is an approach to explore and understand the meanings individuals attribute to a human need. Yilmaz (2013) describes it as an emergent, inductive, interpretive, and naturalistic approach to the study of people, phenomena, and social situations in their natural settings in order to reveal in descriptive terms the meanings that people attach to their experiences of the world. The value of qualitative research allows researchers to study people and phenomena in their natural settings, enabling them to interpret and make sense of the meanings that people give through their lived experiences (Denzin & Lincoln, 2005).

The current study was conducted in the participants' natural setting. They were approached in their own homes where they had full control of their surroundings and made their decision to participate (or not) in the research. The research process entails formulating inquiries and protocols, gathering data usually in the participant's environment, analysing the data and gradually constructing themes from general to specific, and the researcher deducing interpretations of the data's significance. Grove et al (2013) explain that researchers use different modes of interpretations to reach conclusions. This is based on methods of approaching study.

## 3.3: Framework: Ontological and Epistemological Stance

Research methodologies differ based on a philosophical and theoretical view of research that guides researchers in their healthcare research. Healthcare researchers can select a research methodology that depends on philosophical issues related to ontology (the nature of reality) and epistemology (the nature of knowledge). In research, there are two main paradigms used

to understand and structure data: the ontological (quantitative/positivist (scientific) paradigm and the constructivism/qualitative (interpretivist) paradigm. Theoretical perspectives play a significant role in the development of new knowledge (Green and Thorogood, 2004; Streubert and Carpenter, 2011), and understanding these perspectives is crucial for conducting high-quality research.

### **3.3.1: Ontological Position**

Ontology is focused on reality and its defining characteristics. According to Manion and Morrison (2011), it delves into the very nature of the social phenomena under investigation. As a qualitative researcher, I acknowledge that there are various realities that are constructed (Creswell and Poth, 2018). The aim of this study is to present the participants' accounts and viewpoints, which reflect their experiences, and to explore how they perceive these experiences (Smith et al., 2012; Moustakas, 1994).

Considering the methodology for this study, it is relevant to identify the existing epistemological stance, which are positivism or objectivism and interpretivism or subjectivity.

Positivist scholars hold the view that truth is an objective, universal, and quantifiable concept. They argue that reality is consistent and uniform for all individuals and can be identified through the application of scientific methods. The notion further advanced is that science overlooks the capacity of individuals to interpret and derive meaning from their own experiences (Darlaston-Jones, 2007). The positivists adopt quantitative design as their preferred research approach.

Given the current study's research aim, objectives, and questions, the participants needed to provide an unrestricted and personalised account of their lived experiences around support in managing issues related to schizophrenia. This approach ensured the data collected was relevant and aligned with the research objectives. It also allowed for a more comprehensive analysis of the peers. This methodology was selected to guarantee that the data gathered was pertinent and aligned with the research objectives. Additionally, it enabled a more comprehensive examination of the results.

Social constructionists and interpretivists argue that people possess distinctive characteristics that enable them to highlight their differences while recognising the fundamental similarities that unite all human beings (Darlaston-Jones, 2007). Smith et al (2012) refer to Merleau-Ponty (1962) as being concerned with subjectivity. This subjectivity is open to interpretations, and it respects the differences in opinions and meanings- 'Interpretivism' (Bryman, 2012, p30). The

interpretation seeks to grasp the understanding of the phenomenon (that is, support) under investigation.

### **3.3.2: Epistemological stance**

The theory of knowledge is intricately linked to the theoretical perspective and methodology. Epistemology is considered as an inherent part of the theoretical perspective, serving as "a way of looking at the world and making sense of it." (Crotty, 1998: p.3; Al-Ababneh, 2020). The epistemological approach to building knowledge includes objectivism, constructionism, and subjectivism.

Objectivism asserts that meaning and meaningful reality exist independently of any consciousness (Crotty, 1998). It posits that social entities exist in a reality external to social actors. In contrast, constructionism refers to the meaning that emerges through human engagement with the world, suggesting that truth is not waiting to be discovered, and that meaning is constructed through the interaction between the subject and the object. Lastly, subjectivism pertains to the meaning imposed on an object by the subject, independent of the object itself contributing to that meaning.

The approach adopted for this study was a bottom-up approach identified in Ormston et al (2013). It is worth noting that reality is not an absolute, objective truth that exists independently of human experiences. Rather, it is a product of social interaction between individuals who share their perceptions and interpretations of the world (Berger & Luckman, 1966). I chose epistemological and not ontological views as a model to guide this study because my own research topic and methodology were influenced by my adherence to a constructionist worldview. This model guided me to gather participants views about their experiences around support in mental health in Ghana. This is qualitative research based on subjective accounts of the participants and the aim is to understand what constitutes support in the research enclave.

### **3.4: Why Phenomenology?**

Phenomenology purposely seeks to investigate lived experience or the life world (Streubert and Carpenter, 2011), based on Humanistic research and applies qualitative approach (Denscombe, 2003). It emphasises the world as lived by a person and therefore the human factor is paramount as reality is seen as something not separate from the person. The current

study focuses on developing understanding and meanings of the participants' lived experiences in relation to the management of schizophrenia and this is in line with getting to understand the participant's reality from themselves (Valle and Halling, 1989). Smith et al (2012) and Polkinghorne (1983) explain this as an attempt to understand meanings of people's lived experiences. Therefore, the researcher must have the phenomenological attitude to investigate the everyday experiences (lifeworld) of the participant.

Phenomenological attitude is concerned with studying experiences from the participant's perspective while acknowledging the interpretation of the data through the eyes of the interviewer. Husserl (1970) argues that it involves bracketing-off assumptions, horizontalisation (no one meaning is thought to be more important than another), in-depth descriptions, and searching for the nature of the phenomenon. Van Manen (2016) expounds the argument that it is not easy to identify good examples of a phenomenon, but it takes a considerable effort to use pragmatic thinking in the "concreteness and fullness of lived life. In studying the phenomenon, the researcher is in contact with the study participant(s), and there is a temptation for the researcher to influence the data with their biases. Colaizzi (1978) and van Manen (2016) call attention to bracket off pre-understandings, existing knowledge, assumptions, and perceptions of the phenomenon. Although bracketing off our biases from the study is advocated in phenomenological study, Heidegger (1962/1927) argues that it is impossible to maintain objectivity and therefore a degree of bias remains. I align with Smith et al (2012) perspective that effective communication between the researcher and participants can aid in bracketing. Accordingly, I prioritise remaining impartial and focusing on the experiences that arise during research, while acknowledging their potential significance. I refrain from imposing my own beliefs onto participants and instead aim to elicit information about their unique lived experiences.

Another reason for choosing Phenomenological research is based on the premise of 'intentionality' which highlights the inextricable connectedness of humans to the social world. It offers the researcher the chance to investigate conscious experiences. It is explained that perception (consciousness) is closely related to the object visualised (Smith et al., 2012; van Manen, 2016). Intentionality makes it feasible to connect the subjective and objective - bringing unconscious concept to consciousness. The reflection of this bi-polar experience proposes a direction for meanings of a phenomenon, which are constructed within the interaction between the researcher and the research participant. Husserl (1970) explains that phenomenology involves a reflection of individual's experience of their physical body and their relationships with others, which offers their perception of the world around them and how they relate objectively in that social world. Therefore, studying the lifeworld is to gain the understanding of support as people experience it in the social world. The study of the lifeworld,

as experienced pre-reflectively offers direction for hermeneutic phenomenology, which must be explored.

Exploration of a whole person to understand a health-related phenomenon is much welcome in Phenomenology (Mapp, 2008). Using phenomenology helped me to investigate service users, informal caregivers, and professional nurses' experiences within the context of receiving or offering support. Phenomenology offers the opportunity for people's idiosyncratic experiences with support in managing mental disorders to be explored with them to understand their individual experiences to inform services that would meet the needs of its users. Studying support, a crucial aspect of mental health, presents a challenge due to its complexity. Mapp (2008) posits that Phenomenology aims to uncover the core meanings and essential qualities of the experience. By revisiting these experiences, individuals may discover new meanings or be reminded of forgotten ones within their communities and society, ultimately strengthening social bonds. This argument highlights the need for a deeper understanding of support through hermeneutic phenomenology to improve the lives of individuals.

### **3.5: Hermeneutic Phenomenology**

Hermeneutic phenomenology is a type of phenomenology which adopts interpretation to divulge "otherwise concealed meanings in the phenomena" (Spiegelberg, 1975:57). Interpretivism is used to establish connections and meanings within a context, and these relationships help in building knowledge (Lincoln and Guba, 1985; Streubert and Carpenter, 2011). The lifeworld approach takes more than description to be useful (Englander, 2016; Davidson, 2003). Therefore, Hermeneutics provides the backbone for Interpretative Phenomenological Analysis (IPA) which is the methodological approach for the current study. According to Smith et al., (2012, p.21 & 35):

The...major theoretical underpinning of IPA comes from hermeneutics. Hermeneutics is the theory of interpretation. It enters our story as a much older and entirely separate body of thought from phenomenology, ...the two strands are due to meet, in the work of hermeneutic phenomenologists (p.21). There is a phenomenon ready to shine forth, but detective work is required by the researcher to facilitate the coming forth, and then to make sense of it once it has happened (p.35)."

In regard to my work, it is important to note that in order to understand participants' perception of support, both the participants and I aim to make sense of the stories they share. This

process often requires me to provide interpretation to their stories, with the goal of gaining a deeper understanding of the meaning behind their lived experiences.

In studying lived experiences, Husserl (1970) describes it as the world of immediate experience, and this offers the pragmatic view rather than abstraction of the phenomenon. Van Manen (2014) argues that the lived experiences of people are experiences that are conscious. Both Husserl and van Manen's theoretical stance highlights the consciousness, which reflects practical aspects of the phenomenon.

Researchers in phenomenology are tasked to find a way by which someone would understand their own experience of the phenomenon of interest. It is in this light that the current study investigates the lived experiences of research participants, and which must be studied within consciousness. The researcher and the participants are immersed in the search for meaning of the phenomenon. The point is well captured in Smith et al., (2012:3):

“When people are engaged with ‘an experience’ of something major in their lives, they begin to reflect on the significance of what is happening, and IPA aims to engage with these reflections... This attempt by the research participant to make sense of what is happening to them takes us to IPA's second major theoretical axis. It is an interpretative endeavour and therefore informed by hermeneutics, the theory of interpretation.... IPA researcher is engaged in a double hermeneutic because the researcher is trying to make sense of the participant trying to make sense of what is happening to them.” (Smith et al., 2012, p3):

The phenomenon implied in this study as already mentioned is ‘support’ in the management of schizophrenia. Schizophrenia as an illness becomes a major experience in itself for the service user and the caregiver. To be able to manage this major experience, both the caregiver and the service need to offer and accept support. Giving and accepting support represents social phenomenon, which requires interpretation and comprehension, as well as interaction to help build a relationship with the participant. Such interaction would offer knowledge about the needs of the participant. Understanding others is attained through reflection. Therefore, understanding of the lived experienced is gained through interpretation and this is the core of interpretative phenomenological study (van Manen, 2016; Heidegger, 2011).

Heidegger produces tenets to create his version of interpretive phenomenological research which is a shift from Husserl. Heidegger disagrees with Husserl's ideas, maintaining that it was mainly descriptive, and proposes his (Heidegger) theory as a type of interpretation of experience which explores ‘the meaning of being’ (Horrigan-Kelly et al., 2016). Heidegger (2003) dismisses the conception of human being (subject) as an observer of objects

embracing the notion that subject and object are indivisible. Using the term such as “Dasein” (being in the world) or “Da” and “sein” meaning ‘being’ and ‘to be or being there’ respectively, Heidegger argues that something must exist in the world before it can be studied. Heidegger’s existential theory holds that understanding is achieved through everyday activities (Heidegger, 2011). Appropriating “Dasein” to humanity, the concept refers to humans as active players in the social world whose understanding of their lived experiences is achieved through everyday activities (Heidegger, 2011). Humans in this sense are active participants in the research process reflecting on the lived experiences for better understanding.

Moving away from Heidegger’s existential hermeneutics, Gadamer (1995) presents a different approach for studying lived experience. Gadamer proposes a set of principles facilitating the human search for truth in the concealed forgetfulness of language (Regan, 2012). Gadamer’s concept of Dasein suggests that research participants are immersed in the social world and share a phenomenon with others (Regan, 2012). Prima facie of Gadamer’s argument is that research participants’ narrative of their lived experience reflects the general experience of people with similar characteristics. For example, participants’ story about their lived experience (lifeworld) of support in mental healthcare is not limited to only their individual experience but it is an experience relevant to the general management of the mental disorder, which is relevant and akin to universality of human existence. Galvin and Holloway (2015) accentuate this example when they note that the grounds for investigating the identified experiential phenomenon is to seek understanding that has relevance for humanity. Much as the individuals share their story, the onus lies with the researcher to consider the individual’s narratives as a general concern in the community mental health service in Ghana. Therefore, I, the researcher, seek to analyse the experiences shared by the research participants as experiences they share with others in the general population (Regan, 2012; Creswell and Poth, 2018) and the understanding of the lived experience becomes clearer through the interpretation of the participants’ narrative and highlighting its importance to humans.

This chapter expunges the theoretical ideals of research design from chapter Four which describes practical approaches adopted in collecting the data for the study. It discussed the motivation for choosing the design of the research. The next chapter describes the processes adopted in the data collection and analysis.

## **CHAPTER FOUR: METHODS OF THE STUDY**

### **4.1: Introduction**

This chapter progresses from the theoretical basis to the action stages. It showcases the qualitative methods I utilised to gather and analyse data during the research process. The chapter delves into the approach to the field, the researcher's positioning, the research site, the criteria for sample selection, and the data collection methods, which include a semi-structured interview guide. Additionally, I outline the data analysis strategies and provide illustrative examples to support the chosen strategies. Choosing the appropriate research methods was a crucial step in investigating the chosen topic using a qualitative approach. This chapter will explore the methods employed in data collection, analysis, and interpretation. Research methods refer to the techniques used for data collection (Bryman, 2012), and my goal was to determine the most effective methods to achieve my research objectives. The methods I utilised encompassed the various approaches, protocols, and systems that helped me gather, analyse, and interpret data to address my research aim.

The research design and the methods I employed in gathering data for this study are supported by the ontological and epistemological framework explained in Chapter Three. In this chapter, I discuss qualitative methods employed to collect and analyse the data. It specifically covers the approach to the field, my positioning, research site, inclusion and exclusion criteria for sampling participants, the data collection methods including semi-structured interview guide are discussed. Data analysis strategies are described, and examples are provided in support of the strategies chosen. Moreover, the approach to entering the field will be discussed.

### **4.2: Research Governance in Healthcare**

Research governance refers to ethical codes of practice to guide research to safeguard research participants. In the current study, the field work commenced once Middlesex University School of Health and Social Ethics Research Ethics Committee granted ethics approval. The research ethics process involved developing a proposal and submitting an application on safeguarding and risk assessment. After a series of corrections to the initial application, I gained approval from the University ethics committee in 2017, permitting me to carry out research with community mental health service users and their caregivers in Ghana. In 2018, an addendum was made to the already approved ethics application whereby a further

literature review indicated that the staff group was necessary to include in the study. In consultation with the supervisory team, interviewing the staff group was pertinent and the team supported the application for a research ethics amendment. Approval to this application was obtained in May 2018 to enable community mental health staff to be interviewed. A similar application was made to the Ghana Health Service Ethical Review Committee because the staff were to be interviewed via telephone which the previous application did not indicate. I did this to ensure that I follow best research practices to collect data in accordance with the ethical standards of the Middlesex University School of Health and Social Research Ethics Committee and Ghana Health Service Ethics Review Committee.

Gaining access to the research site for this qualitative study involved contacting different managers at different layers of authority in the Ghana Health Service. This is fully discussed under section 4.3 of this chapter.

### **4.3: Entering the Field**

This section describes the processes involved in accessing the research participants and the research area. The study was conducted in an uncontrolled natural environment, where the conditions could not be manipulated by the researcher, presenting inherent challenges. I had to observe and analyse the situation as it naturally occurred, without the ability to control external variables. Challenges included unexpected noises inside and outside participants' homes, as well as instances where participants were unavailable due to pressing assignments, necessitating me to reschedule appointments. In one interview, a participant interrupted the session to perform his ablution and finish his prayer. It was agreed that the interview would be continued after one hour, allowing the participant enough time for religious rites.

#### **4.3.1: Access to organisations and participants**

The fieldwork comprised a combination of research activities, including negotiating with layers of gatekeepers before accessing the relevant participants, recruiting participants, conducting interviews, and ensuring the safe management of data gathered.

##### **4.3.1a: Role of gatekeepers in the current study**

Gatekeepers play a vital role in healthcare research as they have the authority to grant, deny, or delay access to research sites and potential participants (Lee, 2005). Recognising this, I understood that acquiring the confidence of the various gatekeepers is often time-consuming,

therefore I allocated ample time to building relationships and establishing communications with key gatekeepers, including the Chief Executive Officer (the Chief Psychiatrist) of the Mental Health Authority in Ghana, Community Mental Health coordinators at various levels, service managers and clinical staff.

The relevant gatekeepers were contacted at different times to negotiate access to the research participants. The study was given approval at all the levels of communication and management before recruiting participants for the research project, after I (the researcher) had assured the gatekeepers of the safety of the research participants in meetings. This required submitting a proposal of the study to the Mental Health Authority as part of the application and discussing further the importance of the study to the Ghanaian community, especially, with emphasis on finding out the needs of both the people diagnosed with schizophrenia and their caregivers, who are only known as offering support to their sick relatives using the mental health services. Before entering the field, I applied to Middlesex University Ethics Sub-committee for approval and Ghana Health Service Ethics Research Committee (See Appendices 2, 3, 6 and 7).

Contacting Community Mental Health Services for research purposes in Ghana can be quite challenging. This difficulty can be attributed to various factors, including the fear of exposing misconduct, as identified by Murgatroyd et al. (2015). After engaging in a series of telephone discussions with professional nurses and other healthcare staff, I successfully obtained the telephone contacts of six service managers. The Community Mental Health Service managers lead the team of community mental health nurses and have direct service user contact. The service managers were contacted by telephone and for eight weeks, I had regular telephone contacts with them to seek their agreement to use their respective service area for the study. Albut and Masters (2010) identify outright refusal of access to a potential research site when people who wield power dislike the idea of research. Three out of the six service managers rejected the request for using their services for the study after four telephone conversations. The reasons they gave were that their office site was under renovation, they did not know the researcher and did not want their base to be used as a site to investigate the mental health service.

The telephone discussion continued with the other three managers. After seven telephone calls to each of the three service managers, two out of the three declined to participate in the study. One of them was suspicious that the study would find some fault with their service which was described as a young service with a small team. The other manager rejected the request with the explanation that there was a major incident (which was undisclosed for confidentiality) and an investigation was ongoing at the time. Therefore, the service area could not be

accessed for the study to be carried out. At this stage, five out of the six managers had declined my request to use the service they lead and their catchment for this study. Although these service managers provided convincing explanations for non-participation in the research, nevertheless, the managers entertained the fear that I could be an undercover journalist to foment problems for them which could cost them their job. Prior to the study, some high court judges lost their jobs because an undercover journalist had exposed them as accepting bribes (Letki et al., 2023).

It was, therefore, a period marked by fear of talking to strangers; therefore, people feared speaking to others lest they revealed some information that would implicate others. Being aware of the general emotion at the time, I endeavoured to build trust with all the people I encountered and maintained good relations with them throughout the period. Although, some of the managers stated they could not recall the researcher, I never ceased to re-introduce myself and reminded people of the last time I communicated with them. For a principal investigator in my role as a researcher operating among people who lived in genuine fear of being spied on, meant I needed to negotiate access with utmost care, because I was interacting with people who were anxious. They were suspicious because they did not know me. After four telephone conversations, which did not offer any opportunity to convince these anxious managers, I had to stop contacting them.

Only one out of the six Community Mental Health Service managers contacted gave me a positive response to use his team and the locality he covered. It was later revealed that the manager has been involved in many national research projects and expressed his desire to offer his team and their catchment for this study.

Gaining access to the research site for this qualitative study involved contacting different managers at different layers of authority in the Ghana Health Service and Mental Health. As indicated earlier, the gatekeepers in this study safeguard the health and safety of research participants. Therefore, the meticulous approach described was crucial in securing the necessary permissions and support for conducting the research. The approach is consistent with advice by Creswell and Poth (2018) and Bryman (2012). These authors advise that access to the research site must be negotiated in advance for data collection.

In the early part of the PhD programme, I flew to Ghana to meet the local gatekeepers on the advice of the supervisory team. Also, the literature (Bryman, 2012; Creswell and Poth, 2018) suggests that the qualitative researcher becomes familiar with research site. My data collection was hampered by the fact that I needed Middlesex University School of Health and Social Care Ethics approval first, as students were forbidden from entering the field prior to obtaining research ethics approval. This means I could not officially access the field and

complete another application form for local research governance in Ghana. Therefore, I had to wait for the university ethics clearance before formally approaching the Ghanaian institution responsible for research governance (gatekeepers') to complete an application.

To ensure a smooth ethics clearance process for overseas research, it is recommended to obtain university ethics clearance early in the PhD program. Acting on the advice of my academic supervisory team, I traveled to Ghana in late 2016 to familiarize myself with the organisation responsible for approving access to the field. During my visit, I located the Ghana Health Service Ethics Review Committee's (GHSERC) office and obtained an application form. Before completing the local ethics application, I reached out to the Mental Health Authority Headquarters in Ghana to establish a contact. Once I received approval from Middlesex University School of Health and Social Care Ethics, I submitted another ethics application to GHSERC.

The local research ethics committee, Ghana Health Service Ethics Review Committee (GHSERC), has its own requirements for completing an ethics application. This is in consonance with Shaw & Baker (2004) observation that independent regulatory and approval committees have different requirements, and the researcher must work within the committee's own remit and timetable to obtain approval. The refusal of a researcher's application is possible where their application does not conform to the approval requirements of the committee. In light of ensuring approval was obtained in a shorter time, I strictly followed the guidance and sought clarification with the administrator of the committee since the written guidance was scanty. Whereas Middlesex University Research Ethics Committee accepted online applications, the GHSERC required 13 hard copies together with an electronic copy of the same application. The documents required for submission were a set of thirteen copies of the application form, research proposal, a letter from the university, a reference letter from a local supervisor in addition to a receipt for the payment of an application fee of GHS 300.

Securing a local supervisor for the GHS-ERC proved to be a challenging task. Despite the absence of any provisions in the guidance sheet stipulating a need for an international study or an international student to have a local supervisor for their ethics application and data collection, the administrator verbally warned that a written reference from a local supervisor was mandatory to avoid rejection of the application. As per the administrator's guidelines, it is mandatory for the local supervisor to possess a PhD in the relevant field of study and provide a letter of support for the research project. Fortunately, the researcher was able to connect with a helpful senior lecturer at the University of Ghana who was willing to take on the role of the local supervisor and provided the necessary letter of support for the application.

For a foreign research student, the impediment to delayed approval of the research ethics application could be enormous, but accessing accurate information is crucial to efficiently process an application and receive timely approval. In fact, according to Buchanan et al (2014), luck counts in research. Having a friend referred me to the appropriate individual was a fortunate circumstance for me seeking to complete a local ethics application.

Buchanan et al (2014) propose a four-stage approach for field researchers to navigate when negotiating access to their research site: (a) getting in, (b) getting on, (c) getting out, and (d) getting back. In my case, the "getting in" stage involved a combination of a bottom-up and top-down approach. The initial point of contact was made with the Chief Psychiatrist, who also serves as the Chief Executive Officer (CEO) of the Ghana Mental Authority, through the regional Community Mental Health Manager. This connection allowed for the establishment of a relationship with the Chief Psychiatrist.

The CEO tasked me with building a strong connection with the individuals at the grassroots level, where the participants and operatives are located. The CEO subsequently requested assurance that this connection had been established and that I was well-acquainted with potential participants before granting official approval to access the research participants. The CEO gave an approval for me to conduct the data collection after I submitted a copy of my local ethics clearance to his office.

I established connections with the community mental health nurses in the research enclave, using a bottom-up approach preferred by the CEO of the Ghana Mental Health Authority. Building a rapport with nurses was easy and proved invaluable as I needed them to introduce me to the service users first. The Team Manager agreed to allocate a nurse to escort me to service users daily from Monday to Friday throughout my fieldwork. These are nurses who work with service users. The team manager drove me to all their community units in the enclave one day and introduced me to the nurses at those centers before I was able to recruit participants for the study. This personal introduction was particularly significant as an international researcher needing to gain access to the field.

Recruitment of research participants involved attending team meetings of the Community Mental Health Service in Ghana to promote the research project. McEvoy and Richards (2007) identified that Community Mental Health Services present as gatekeepers, and they must be aware of my presence and my intentions. Woodall et al. (2010) identified distrust as a key factor contributing to barriers to participating in mental health research, and such distrust underlined the aforementioned service managers' outright refusal to allow me to recruit participants from the catchment area. Previous experience in practice indicates that in mental health, local safety practices and risk assessment policies required me to liaise with staff

before contacting service users for research visits. Sharkey et al., (2010) argued that in mental health services, the service user or participants can be recruited by following the local policies which to an extent requires the researcher to consult with the team managing the service user's treatment. Therefore, recruiting service users in consultation with the staff helps to minimise negative staff attitudes to the research and ensures the safety of service users and the researcher. During the handover session, the staff shared information about the service users under their care. Additionally, the team furnished me with a comprehensive service user register and contact details. The information proved useful in aiding the recruitment process for the study. To gain a better understanding of the service users, I accompanied the staff on their home visits during my initial visits.

Upon being introduced by the staff, I familiarised myself with the service users and their caregivers, informing them of my intention to reach out at various intervals to discuss the research study. In order to establish rapport and obtain further information, I returned to the potential participants individually, offering a detailed briefing and fostering a sense of trust. Appendix 14 shows an example of conversation I had with the service users and the caregivers before recruiting them into the study.

Research visits to all service users and their caregivers created the opportunity to establish rapport and share information about the study, whereby the participants were given the participant information sheet (PIS) (Appendix 8 and 9), which provides a comprehensive overview of the research study, outlining the expectations for participants and emphasising that participation is voluntary. It is crucial that participants are not coerced in any way, as this goes against the Middlesex University Code of Practice for Research (2016). The researcher is responsible for upholding ethical research practices, as outlined in the Middlesex University research practice code. The PIS also includes information about the researcher's obligation to prioritise the safety and well-being of both participants and the researcher. By providing clear and concise information about the study procedures, the PIS enables potential

participants to make an informed decision about whether or not to participate. Additionally, the PIS serves as evidence that the participant has been fully informed about the research study.

Following an initial conversation with participants about the study, a consent form and PIS (Appendices 10 and 11) were left with the participant to read and to help them decide whether to participate in the study. I ensured that the prospective participants were provided with ample time to review the PIS and the consent form before joining the study. This was done in accordance with the ethical principles outlined in The Nuremberg Code of 1947, which

emphasised the need for voluntary consent of participants. Therefore, a maximum of one week was provided to encourage voluntary participation in the study. The code states that the voluntary consent of research participants is important (Rebers et al., 2016; Mitscherlich & Mielke, 1949). A contact number was left for the prospective participant to call if they decided to participate in the study. People who called and indicated their willingness to participate in the study were visited again for the purposes of signing the consent form. The consent form was jointly signed by the participant and I as the researcher after I had checked again with the prospective participant that they had indeed made an independent decision to participate in the study. This approach of obtaining the written consent is in line with the United Kingdom Medical Research Council's (2020) guidance which advises in favour of obtaining written and informed consent.

The people who did not call to show their interest were not contacted again as I did not want to demonstrate any coercion of such individuals.

Having gained the formal consent of participants to engage in the study, the participants were individually interviewed in face-to-face interview sessions which lasted between 60-90 minutes, which gave them ample time to share information about their lived experiences in the comfort of their own homes. The interviews were transcribed for analysis.

#### **4.3.1b: Seeking Informed consent.**

To ensure informed consent, I explained to participants that their participation in the study was voluntary and that they could withdraw at any time without any obligation (Grove et al., 2013). Prior to obtaining their consent, I provided a detailed explanation of the study's objectives, why they were selected to participate, the duration of the interview, the potential benefits of their involvement, any potential risks, and their right to confidentiality and non-disclosure of any information. It is important to provide participants with sufficient information to enable them to understand the study's requirements and expectations (Wood & Ross-Kerr, 2011).

After accompanying the community nurses on their visits to each service user and caregiver, I took the initiative to follow up with prospective participants the next day. During our one-on-one meetings, I provided them with an information sheet and a copy of the consent form, and we went over the PIS in detail. I encouraged them to ask any questions they had and assured them that they could keep the information sheets for future reference. To facilitate further communication, I also provided a local mobile number for them to contact me if they needed any additional clarifications about the study. For those who expressed interest in being interviewed, I gave them a week to consider their decision and get back to me. Once they

confirmed their willingness to participate, we arranged a time to meet again and sign the consent form.

Prior to obtaining their consent, I ensured that they were fully informed of the PIS and comprehended the information and its requirements. I reviewed the PIS with them once more to confirm their understanding of all the details included in the document and emphasised that participation in the study was entirely voluntary. Once they expressed their desire to sign the consent form, I furnished them with two copies of the document for their signature. I observed them sign their portion of the consent form in my presence, and they witnessed me sign the researcher's portion. They retained one signed copy and I retained the other for my records.

Of relevance to the current study, when collecting data, it is crucial for researchers to demonstrate punctuality and patience with their participants. Kraft et al (2021) emphasise the significance of these qualities, as they convey respect towards the participants. In qualitative research, applying hermeneutics requires researchers to empathise with their participants and, if possible, offer to reschedule the interview at a more convenient time. This approach can help put participants at ease, especially if they are busy with other commitments. By understanding their situation and handling it with care, researchers can encourage participants to open up about their lifeworld, which can provide valuable insights for the study.

## **Summary**

Building and nurturing trustworthy connections with gatekeepers is crucial for gaining entry into a field. However, sustaining those relationships with busy gatekeepers can prove challenging. This was particularly true for senior members who often failed to recall previous encounters with me. As a result, reintroducing myself was necessary before any productive conversation could take place. The challenge I faced undermined the significance of our discussions. For example, when I inquired about their organisation and related documentation but was informed that we schedule another time for discussions as the necessary preparations had not been made or a higher-up was not available to grant access to the requested document. Despite meeting with senior-level gatekeepers in person, I was directed to seek assistance from junior officers. Although the staff I encountered at the various organisations recognised me by sight and sound, they were unable to retrieve the documents I needed without first obtaining approval from their superiors. According to Wielden (2016) administrative processes require researchers to exhibit qualities such as politeness, humility, respectfulness, punctuality, patience, and non-judgment. As I reflected on my own research journey, I realized that I would need the assistance of others in the form of conversations, encouragement, suggestions, and advice. While I initially struggled to connect with the right

people, my persistence in building relationships with gatekeepers and participants and being visible in their offices eventually led me to the support I needed.

By exhibiting patience, politeness, and adaptability, I was able to engage in more meaningful conversations with the people I encountered. As they realised that I was not attempting to deceive them into divulging confidential information, but rather conducting research for my PhD, their apprehensions dissipated. Some of the gatekeepers even shared their plans for future studies and sought my input. To be a successful qualitative researcher, it is crucial to have a genuine interest in the needs of others, so as not to become overwhelmed and stray from the intended course of action. Prioritising the needs of individuals is a fundamental value to uphold in this research study, and the researcher's positioning plays a critical role in achieving this.

#### **4.4: Researcher Positionality: An in-between (Insider-Outsider) Researcher**

This study crucially also accounts for the role of the researcher by examining the researcher positionality. This is essentially due to the vital role the researcher's positionality plays in establishing or undermining the rigour of the research (Kraft et al., 2021; Johnson et al., 2020).

Being reflexive in the field means that the researcher is encouraged to be self-aware of their own presence, biases and position on the research relationship, and this relates to the notion of 'insider-outsider' research (Fineffer-Rosenbluh, 2017). Reflecting on the fieldwork notes and my positioning, my background as a Mental Health Nurse practitioner was beneficial. My years of practice in different clinical settings in the United Kingdom has equipped me with a stock of knowledge and skills in working with service users in both inpatient and community mental health settings, with caregivers, in multidisciplinary teams and multiagency settings. I am skilled in interacting with people from similar professional backgrounds, however, the difference in this research study location was that I worked in a different country and not as a practitioner but as a researcher. Sharing in the view of Milligan (2016), as the researcher, I felt that I adopted 'shifting identities' in different research situations, which Wegener (2014) argues is useful for accessing valuable information. For instance, having a mental health nursing background, meant that I shared a similar identity with the nurses that I encountered in the field, which was of benefit in terms of the level of support I received in accessing information about service users and their families in the research site. This enabled me to recruit participants for the study. The positioning of researchers in qualitative studies describes the extent of power they hold in the research process. The three strands of positioning are 'insider', 'outsider' and the 'space in-between' Bukamal, 2022: Dwyer and Buckle, 2009). Griffith (1998) considers an insider researcher as 'someone whose biography (gender, race, class, sexual

orientation and so on) gives them a lived familiarity with the group being researched'. In the context of the current research, this 'insiderness' is viewed in relation to common characteristics, such as knowledge of the culture and language shared by the researcher and the participants. Bromme et al (2001) identify a correspondence hypothesis as a kind of knowledge that indicates some closeness. Considering the familiarity of the Ghanaian culture, the participants and I share similar (cultural) knowledge which offers a common platform for us to engage in dialogue with no power imbalances. The egalitarian relationship is exemplified in the current research where the participant was a source of raw data, and as researcher, I had the capacity to convert the raw data into more meaningful data (Fedyuk and Zentai, 2018).

In order to fulfil my role effectively and efficiently, I needed to recognise and respect the unique perspectives of each participant without allowing my personal biases to influence their views. It is important to understand that truth is subjective, and there is no one definitive answer, as acknowledged by the interpretive paradigm. Therefore, I prioritised negotiating participation with each participant from the outset and was attentive to their level of involvement in the study (Birch & Miller, 2012). As an 'insider' researcher, I must remain self-critical and constantly evaluate my role in the research process. As a nurse, I bring a broader perspective, informed by my previous knowledge and personal experience of the factors that contribute to maintaining good mental health. I am mindful of the importance of maintaining both familiarity and credibility throughout the study.

The collaboration between the participants and I ensured information generation and the co-production of knowledge, which contributes to the findings of the study. In such circumstances, both the participants and I as the researcher are equally valuable to the data gathering process. As stated by Merriam et al (2001), participants who shared similar characteristics with the researcher tended to form a closer connection. This aligns with the current study, in which participants and I established a warm rapport due to our shared cultural background and ethnicity. My proficiency in the local language, widely spoken in the research location, along with my practice of greeting participants in their native language and in Twi, contributed to strengthening the rapport-building process. The aforementioned attributes further strengthened the bond between the participants and myself, creating the impression that I was an 'insider.' Furthermore, by demonstrating empathy towards the participants during the data collection phase of this study, they began to view me as someone who genuinely comprehended and empathised with their experiences.

Empathy and compassion in the research relationship are important, especially in a society where attitudes towards mental illness are stigmatising. Hence, the approach to researching mental health issues must be done in a positive light. To gain insider status, it is argued that

human interactions must be moderated by empathy and understanding (Moudatsou et al, 2020) and cultural values and practices (Yanow and Schwartz-Shea, 2009). Common shared values, such as showing genuine interest in the sick person's situation and prioritising people first, fostered a sense of trust between the participants and the researcher. These values helped create a strong foundation for open communication and mutual understanding throughout the research process. Having a similar cultural background, where there is a pervasive stigma towards mental illness, enabled me to interact with participants in ways that were culturally sensitive and appropriate (Mulhall, 2002). Leveraging my understanding of emotional intelligence, I was able to maintain a respectful and composed demeanour during interactions, which encouraged participants to express themselves freely and engage actively in meetings and conversations. This approach not only facilitated open dialogue but also empowered participants to feel more at ease and appreciated throughout the research process.

Furthermore, I often approached participants with a sense of curiosity and asked probing questions to gain a deeper understanding of their experiences. By intentionally maintaining a position of limited knowledge, I was able to establish myself as an impartial observer. This outsider perspective allowed me to learn more from the participants and enhance the quality of the interviews. For instance, service users and caregivers were able to provide detailed insights into their support experiences without feeling constrained by preconceived notions that I may have held.

As someone conducting research in a country where I no longer reside, I often feel like an outsider - a 'non-member' of the research location, as Mercer (2007) notes. This sentiment strongly aligns with my own positionality, as I have experienced differential treatment from some participants simply because I am not a professional health practitioner within the research enclave. In particular, certain qualified mental health nurses were unwelcoming when it came to granting me access to service user and caregiver participants.

Despite my reminders that I needed to speak to non-professional participants individually and without staff involvement, these mental health nurses preferred to sit in on the service user interviews. The aim of speaking to participants individually to ensure that they felt comfortable speaking freely during the interview without feeling intimidated by the presence of their key worker. Additionally, it was important to maintain confidentiality and minimise the possibility of staff harassing participating service users to know what had been discussed with the researcher by keeping the identity of the participants unknown to the staff nurses. As a researcher, I made a commitment to ensure the confidentiality of my participants. In qualitative

research, it is my responsibility to address any concerns regarding confidentiality when staff members attend meetings with service users (Kaiser, 2009).

Confidentiality refers to the agreement between the researcher and the participants regarding the use of their data (Sieber, 1992). To comply with the guidelines set by Middlesex University's Research Ethics Committee and the Ghana Health Service Ethical Research Committee (GHSERC), each participant in the study was required to read and sign an informed consent statement prior to the interview. The consent form explicitly stated that any reports resulting from the study would not include any information that could reveal the identity of the participants. For example, "All information that is collected about you during the course of the research will be kept strictly confidential" and this is to ensure that readers will not be able to link the participant to the study. The research enclave's nursing staff were required to maintain a strict blind protocol to prevent any knowledge of study participants.

At a team meeting that included nurses, their manager and I arrived at a resolution for the completion of data collection in the field. The manager instructed the nurses to follow my request during the data collection process. Ritchie et al (2009) and Holmes (2020) explain that a researcher's' neutral position is important to learn about the participants' perceptions. Adopting a similar approach during interviewing, I always informed the participants that I, the researcher, was interested in their stories. I did not know much about their personal experiences and so went to the field without any preconceived ideas, ready to receive information and knowledge from the participants about their lived experiences. This helped me to assume an 'outsider' status to enable me to probe their stories. This stance was useful to deter me from imposing ideas on the participants. The participants had the power to share their stories. This is consistent with Interpretative Phenomenological Approach in full which makes use of lived experiences. (Smith et al., 2012).

In course of interviewing, there were shifting positions of my role as the researcher and the participants, between insiderness and outsidersness. On many occasions when participants felt appropriate to shift from the responsibility of answering a particular question, they would throw it back to me to offer the answer they thought would be suitable. For example, asking about the assistance a participant caregiver would need to continue to support the sick relative, the participant stated money but could not suggest the exact amount that they would need and invited me to give a befitting figure for them. Asking about the assistance required by caregivers was to enable me gain an estimation of how much the caregivers spent on their relatives. However, considering my researcher as an insider, the participant perceived I knew more about their plight and felt I was the right person to help answer the question. Similar sentiments were expressed by another participant when they invited me to answer a question

about the participant's religious views on the cause of schizophrenia. There was a sense that I was more knowledgeable about the participant's religious faith and the illness. However, I explained that I did not belong to the same religious sect as the participant and, therefore, was uncomfortable to discuss their faith as the research was about the participant's experience in relation to support around managing schizophrenia. Thus, views on the neutrality of the role of researcher to ensure the participants discussed their experiences was important and meant that I actively shifted my position to one of an outsider in the research relationship.

Within one meeting and participant interaction, there were shifting positions between being an insider and an outsider. For instance, in interactions with the staff group, some staff members perceived me as an outsider and would prefer spelling out the various nursing hierarchies, knowing I was not locally trained and had not practised in the country. In the same conversation, I, the researcher became an insider when we discussed professional roles.

To conclude, the above accounts in the field demonstrate the shifting positions of insiderness-outsiderness that I experienced as a researcher, frequently adopting a 'in-between' position and identity in navigating and negotiating the research relationships with service users, caregivers, and mental health nursing staff.

#### **4.5: Research Setting**

Ghana has been chosen as a country for this study for the purpose of learning about how the research phenomenon, that is, social support in mental health, is perceived and experienced in a predominantly extended family culture. Moreover, Ghana has been chosen because negligible research has been conducted on this topic. However, a small section of the country, an administrative district, La-Nkwantanang-Madina Municipality was selected.

Learning from the service users and their caregivers in their own familiar and natural background offers rich information to the study. The setting for data collection remains the critical area of difference between qualitative and quantitative studies. Data was collected in the participants naturalistic setting (LoBiondo-Wood & Haber, 2022). The participants' own physical setting provided some comfort and familiarity and, therefore, offered the participants some control and safety.

Collecting data from the participants from their naturalistic setting provided an advantage for the researcher to observe and understand the participant values (LoBiondo-Wood & Haber, 2022; Polit and Beck, 2012). Qualitative studies conducted in such natural settings make use of unspoken things, such as home environment, to inform and enrich the narrative data collected.

The study was conducted in the La-Nkwantanang-Madina District/Municipal Community Mental Health Service in the Greater Accra Region of Ghana. As mentioned previously, there are three state specialist mental hospitals in Ghana, namely, Ankaful near Cape Coast in the Central Region, Accra Psychiatric Hospital and Pantang Mental Hospital, both based in Accra. The La-Nkwantanang District has one of the three state specialist mental hospitals in Ghana, that is Pantang, located in it.

In addition to the state specialist mental hospital, the district has satellite centres in more than three public health facilities (community health centres). They are Madina Polyclinic, Keteke Polyclinic, Rawlings Circle and Danfa Health Centre. These satellite centres have existed as the community mental health service lacks their own office building, and it is where they can conduct their routine operations from. Currently, the district head of the community mental health service has an office in Pantang Hospital while the other staff are based in the other public health facilities in the district.

La-Nkwantanang-Madina Municipal Assembly is divided into nine electoral areas. The municipality has a fast-moving population dynamic due to significant population migration from other parts of the country. The fast population growth due to migration poses significant threats to the general management of health, security, education, the environmental, jobs and infrastructure among the inhabitants (Ghana Statistical Service [GSS], 2014). Therefore, the Municipal Administration has the enormous task of ensuring its teeming population is catered for by ensuring health, security and other service facilities are provided.

La-Nkwantanang-Madina Municipal Assembly covers the northern part of the Greater Accra Region. It is one of the sixteen Metropolitan, Municipal, and District Assemblies in the region and covers a land area of 166 square kilometres. It is bordered on the west by another Municipal Assembly (GEMA), on the east by the Adentan Municipal Assembly (AdMA), the south by Accra Metropolitan Assembly (AMA) and the north by the Akwapim South District Assembly (GSS, 2014).

The municipality has both urban and semi-rural areas. Semi-rural because the area is fast developing due to the influx of migrants, who need accommodation and are putting up new buildings in what used to be rural areas about five years ago. The physical development has changed the rural setting to make it appear close to being an urban setting. The only feature yet to be improved is the road network to these developing areas (GSS, 2014). Some areas in the municipality include Madina, North Legon, Social Welfare Institute area, Akatsi Abor, Okataban and La Nkwantanang. Madina serves as the administrative hub of the region and has emerged as a thriving centre for commercial and business activities. It falls under the jurisdiction of the municipality and plays a critical role in driving economic growth and

development in the area. North Legon, Akatsi Abor and Okataban represent the major urban residential communities within the municipality. Although, places such as Oyarifa, Teiman, Ayimensa, Danfa, Otinibi and Pantang are considered rural communities, the pace at which modern housing is being constructed is changing these rural areas into urban settlements (GSS, 2014).

The Municipality has one of the big market centres in the Greater Accra Region. The market attracts people from different parts of the country and has, therefore, has a diverse ethnic representation (GSS, 2014). The market provides many jobs for its inhabitants. However, much depends on one's financial standing to be able to engage well in trading activities. On paper, it is one of the rich municipalities in the region, however, there is stark poverty among families who do not command good financial resources (GSS, 2014). Many of the stall owners travel outside the municipality to transact business.

The Municipality is a multi-faith community. The evidence identifies faith groups as including the following: 'No Religion', Catholic, Protestants (Anglican Lutheran), Pentecostal/Charismatic, Other Christians, Islam, Traditionalist, Other religions (GSS, 2014). All religious adherents co-exist with each other in a more tolerable manner. The majority of the inhabitants are migrants from other parts of the country but live peacefully with the native dwellers. The sampling and recruitment strategies are the next stage for discussion.

#### **4.6: Sampling and Recruitment of the Participants**

This section aims to describe the process of selecting interviewees for participating in the current study.

La-Nkwantanang-Madina Municipal Assembly Health Service District was chosen because of access to a senior member of staff who oversaw the Community Mental Health Service. The Community Mental Health service has 20 adult patients diagnosed with schizophrenia on the service's register. The service users live in their homes and are meant to have regular visits from the Community Mental Health nurses. The Community Mental Health team operate from the polyclinics in the district due lack of office space to house the team. The staff are based in satellite centres, which offers some degree of benefits to the service users who can easily access the polyclinic near their home should the need arise.

The study recruited 37 participants (namely, 10 service users diagnosed with schizophrenia, 21 caregivers, and six community mental health nurses who are professionally trained) who satisfied the inclusion criteria, see 4.6. The demographic details of the 37 participants are presented in Tables 5.1, 5.2 and 5.3.

All the 37 participants initially consented to participate in the research. In my contact with the participants, I was optimistic that these men and women were communicative and would bring valuable, diverse, original and insightful information of their experiences as service users, caregivers and professional nurses, and their perceptions and experiences of support around managing schizophrenia. As a researcher, I made initial contact with each participant by face-to-face contact. It was reassuring to meet people who were eager to sacrifice their time and themselves to be part of this research, that would seek to inform future improvement in the practice and management of mental healthcare in the country. Most of the people conveyed their enthusiasm and eagerness in the project and expressed that the findings would help make changes to the running of the mental health service in Ghana.

#### **4.6.1: Inclusion and Exclusion Criteria**

The study utilised the purposive sampling technique, which selects research participants based on specific qualities and for reasons that answer the research question (Teddlie & Yu, 2007). Purposive sampling in qualitative research seeks to recruit participants who become the source of the data and can furnish and expand on the data necessary for achieving the research study aims (Grove et al., 2013). In this study, the rationale for choosing purposive sampling is in line with Grove et al. (2013) whereby the researcher chooses participants with a diagnosis of schizophrenia and who live in the research site and are willing to share their experiences. These participants are the service users, caregivers of the service users and the community mental health nurses. The participants were chosen to help gain insight and in-depth understanding of support which has not been studied in the country.

The essential criteria for inclusion for service users were based on the individual being a registered service user with an official diagnosis of schizophrenia, residing in the catchment of the La-Nkwantanang-Madina Municipality, receiving antipsychotic medication as treatment, and who are aged between 18-60 years. Gogtay et al., (2011) explain that the age of onset of schizophrenia is late adolescence and early adulthood. Therefore, it is reasonable to include participants who are between 18 years and 60 years as the upper age limit is consider individuals within the working age group. In Ghana, pensionable age is 60 years, and the present study sought to recruit participants from an active working age group.

The inclusion criteria for caregivers are those between 18-60 years of age. Again, this is to include participants from an active and working age group of caregivers, who must reside within the study enclave and/or supports a service user with a diagnosis of schizophrenia residing in the study enclave. The caregivers must be involved in the care of the service user.

The criteria for recruiting staff participants were that they must be a qualified mental health professional, working in the community mental health service in the enclave. The mental health nurse must have direct contact with the community mental health service user with schizophrenia.

The exclusion criteria for this study were people who lacked capacity to consent to the study, who did not reside or work in the study enclave and people who were described as experiencing a mental health crisis, where "crisis" refers to current hospitalisation (both mental health and general hospitals) and a current unsettled mental state (Palmer *et al.*, 2013; Patino & Ferreira, 2018).

#### **4.6.2: Recruitment of Service User Participants**

I attended team meetings in the Community Mental Health Service Team's office based at Pantang Hospital that serve the local community. The manager first introduced me to the staff and gave me the opportunity to address the team. I shared information about my study and requested that I approach the service users' in their homes, by visiting with the nurses. I declared my intention of purposively recruiting service users and their caregivers for the study. I then asked the community mental health staff nurses to give me a handover on service users on their caseloads who had a diagnosis of schizophrenia. Following the handover on service users, I planned visits to their homes with the staff. I requested and had a list of all service users, they were twenty-two in total, with a diagnosis of schizophrenia as mentioned earlier, from a senior nurse who was the Assistant Manager. Out of this number I was able to interview 10 service users.

I decided to see them all face-to-face as a way of ensuring that they all had an equal chance of being considered for the study. My approach of meeting service users face-to-face was also to ensure that each service user approached had the opportunity to see me and decide whether to join the study. This is in line with Sharkey *et al.* (2010) who argue for service users to choose to participate in a study.

Service user participants were approached through initial researcher and nursing staff visits. Once the nursing staff introduced me to the service user and their families, I spoke to the service users about the study and gave them the participant information sheet (Please, see appendix 9). I made service users aware that I would visit them again and discuss the content fully.

Service users were given a minimum of 48hrs to decide their involvement once they had received the participant information sheet. This was to ensure, that I met with each service

user without the presence of their lead nurses. On the second visit and in a one-to-one meeting with the service user, I discussed the participant information as promised in their first meeting. In the discussion, I made service users aware their participation was voluntary, both verbally and in writing and that they could withdraw from the semi-structured interview at any time, but to withdraw their data from the study would take one month following the interview, due to the data being analysed. Furthermore, the service users were informed they could withdraw from the study without it affecting the care they received from their clinical team. Again, this was in line with the principles of autonomy, justice and fairness by Beauchamp and Childress (2019). Although the data collection for the study was essential, respecting the rights and wishes of the service users remained my priority throughout the research process. I welcomed questions from the service users. Some questions that they asked included:

- Will the nurses know the details of the recorded conversations?
- Will they be penalized for speaking their mind in sharing their experiences?
- Was the meeting going to be between only two people as stated?

When I was satisfied that the service user had understood their role in the study and confirmed interest in participating, they signed two copies of the consent form. A copy of the signed consent form was left with the newly recruited participant for the study.

While deciding who to visit for the second time, I strictly followed the inclusion and exclusion criteria for the study as mentioned earlier and presented in the approved ethics application. The study required between 10-15 service user participants from the research site, considering that selection was based on the individual's interest to join the study, that the service user was stable in their mental state for the last four weeks and at the time of the study, had expressed their willingness to participate in the study. The next section for consideration is the recruitment process for caregivers.

#### **4.6.3: Recruitment of Caregivers**

The caregivers were purposively recruited because of their experiences with caregiving for a person diagnosed with schizophrenia. The recruitment of caregivers followed a similar approach to that of the service users. I obtained information about the caregivers of the individual service users from the Community Mental Health nurses, before the initial visits to their homes. During home visits, I asked the families to identify who was the main caregiver for the service user. Information obtained from the families confirmed the list of caregivers identified initially by the nurses prior to visits to their home.

I engaged in person and in one-to-one meetings. The first meeting lasted for at least 30 minutes and entailed the nurses introducing me to the service users and their families because they were meeting me for the first time. Although I met the caregivers during the initial meeting with the service users, I went back to the caregivers after the service user recruitment had been completed. I visited the caregiver only and introduced the study to the caregiver participant. The participant was not required to make a decision about joining the study during the first meeting. I shared the participant information sheet with the caregivers after I had briefed them about the study separately from the service user that they supported.

The caregiver was similarly given a week to read information about the research and to decide whether to take part.

Stage 1: Service users
Stage 2: Caregivers
Stage 3: Nurses

Figure 4. 1: Stages of recruiting participants

As explained in Figure 4.1 above, the caregivers were the second group to be recruited. One caregiver I approached declined to my request to join the study. Her reason was that she had done many interviews in the past but did not get help from any of them. She was never approached again.

I arranged to see the caregiver, who agreed to join in the study, a second time. The second meeting discussed the participant information sheet detail with the caregiver. At this stage, I allowed any questions the participants had, and all questions were answered. Most times, caregivers expressed understanding of their role in the study. On the whole, only one caregiver asked if they would be paid for their participation in the study, and the answer was that no one participant would receive any financial incentive for the study. I reiterated that their involvement was voluntary. When they agreed to join the study, they signed two consent forms as explained already. All the participants recruited to the study met the inclusion criteria set in the ethics approval and participated in the study of their volition.

#### 4.6.4: Recruitment of Nurses

Following data collection with the service users and the caregivers for this study, I reflected on the dynamics of data already collected and noted that an important data set was missing.

To complete the data collection phase, I felt that obtaining staff perspective in this study was pertinent, particularly as the mental health nurses were involved in caregiving in the community setting and, hence, their perceptions and experiences were also relevant. This necessitated another ethics application that was submitted to the Middlesex University Ethics Committee and the Ghana Health Service Ethical Review Committee for approval. After obtaining ethics clearance from the two bodies, an additional data set was sought from the staff group. Therefore, recruitment of nurses/clinical staff to the research study became mandatory to offer their perspectives from the staff group.

The nurses working in the Community Mental Health Services (CMHS) in the research catchment (La-Nkwantanang-Municipal Area) were the staff participants for this study. I attended CMH Team meetings in the municipal district office which is the central point for the CMHS. There are three different satellite units in the CMHS team. These satellite units are located in the three Polyclinics serving their respective communities. The staff were invited to participate in the study after I had met with them during the fieldwork and had worked alongside them at the time. This was done by emailing an invitation to the team through the team manager. The team does not have any work email address. The manager advised that the only way to reach the team was through a manager's email. The manager then put the invitation on the staff's e-notice board. The interested staff contacted me by telephone. The interested staff were given a participant information sheet together with the consent form individually via their personal email and were given time (a week) to decide on participation. It was believed that a week was sufficient for participants to weigh the reasons for their involvement whether or not to participate, before committing to the study. This was in line with Beauchamp and Childress' (2019) submission that autonomy of individuals must be respected at all costs in all health care dealings.

Once the nurse understood the advantages of participating in the study, they informed me by telephone. I then discussed any queries they had. The main issue that cropped up among some of this group was remuneration for their time, and three staff had quoted an equivalent of £150.00 (approximately 1000 Cedis in Ghana in 2018) each for their time. It was explained to the participants that I could not pay any participant for their involvement in the study, due to being a student researcher and non-availability of funds to pay participants. Moreover, participating in the study was voluntary. The three staff opted out of the study purely on the grounds of not receiving payment for participation in the study.

The nurse who decided to participate in the study and signed the consent form were made aware of their responsibilities in the study as contained in the informed consent. The recruitment and consent process were critically examined by the research ethics committees

and the research degree supervisory team to ensure that the research participants would participate of their "own" volition (Smajdor et al., 2009). The consent process required a thorough discussion of all information on the participant information sheet and the nurse participants only signed the consent form once I was confident that they understood the research process and that they were not participating for any monetary gains. Nurse involvement in the study commenced once the consent form was signed and this confirmed their formal participation in the study.

Following consent to participate in the study, the individual nurse participants chose the day and time they were available to be interviewed. On the agreed appointment, I first sent a text message to remind the participant at least an hour before their telephone interview and called promptly. Like the service user and caregiver interviews, the staff interviews were audio recorded with their permission. Pseudonyms were used throughout in order to maintain confidentiality and protect the researched, as indicated in the research ethics application for this study.

#### **4.7: Semi-structured Interview Guide**

The integration of interviews in healthcare research is to collect qualitative data relevant to the subject being studied and to meet the aims and the objectives of the research. Pietkiewicz and Smith (2012) stated that the use of the semi-structured guide (SSG) in one-to-one interviews is suitable for the Interpretive Phenomenological Approach. Smith et al. (2012) and Paton et al (2014) identify the semi-structured interview as an appropriate format for Interpretive Phenomenological Analysis to gain an in-depth understanding of the lived experiences of study participants.

The hub of the research design is to explore meaning and perceptions to gain understanding, by employing qualitative interviewing where participants are motivated to share in-depth information about their perceptions and experiences of support. Researchers such as DiCicco-Bloom and Crabtree (2006) suggest that the contribution to knowledge is based on the meanings of the lived experiences of the participants. Smith and Osborn (2003) argue that the meanings that the participants draw from their particular experiences become the focus of the interpretative phenomenological analysis. The meanings can be drawn from the exploration of specific events through interviewing, which encourages participants to share their thoughts and feelings. In the current study, I encouraged the participants to talk freely by indicating to them that I wanted to understand 'their' experiences; I wanted to listen to them individually but not to judge them, and to make references to their stories in the final report. My

encouragement to the participants was based on the explanation that IPA's focus is to understand and communicate the perspectives offered by the research participants, in order to 'give voice' to the experiences of their personal and social reality (Larkin et al., 2006). This study used the semi-structured interview guide for data collection.

I constructed three semi-structured interview guides (one each for service user, caregiver, and nurse groups) and attached to the ethics documentation as required in the ethics application process (Appendix 11, 12 & 13). The construction of the semi-structured interview schedules was guided by a review of the literature.

The semi-structured interview guide helps in collecting data for the study (Green & Thorogood 2014, Punch & Oancea, 2014). Semi-structured interviews outline topics to cover and the questions around the topics offer participants the chance to elaborate on their notions and experiences (Sechrist and Pravikoff in Parahoo, 2014; Grove *et al.*, 2013). Being an explorative study about lifeworld, there was minimal guidance on participant's responses and this made semi-structured interviews the most appropriate approach for gathering data for this study. The semi-structured interview provided a degree of flexibility for both research participants and I to explore the phenomenon under study. Of importance, semi-structured interviews are commonly used as a method of data collection in qualitative research (DiCicco-Bloom & Crabtree, 2006; Grove *et al.*, 2013; Holloway & Wheeler, 2010), and especially in healthcare research to explore the experiences of healthcare professionals (MacMartin et al., 2023). My approach to collecting data conformed to MacMartin et al (2023).

The semi-structured interviews have been eulogised by feminist researchers, arguing that structured interviews are inflexible and patriarchal, and foster relations of hierarchy during the research interview process (Punch & Oancea, 2014), whereby the researcher is in a more powerful position vis-à-vis the interviewee.

In my current study, semi-structured interviews were an appropriate choice to avoid the rigid questioning hierarchy associated with structured interviews. By comparison, semi-structured and unstructured interviews are considered as non-hierarchical in terms of levelling the power relations between the researcher and interviewee (Punch & Oancea, 2014), and, hence, this is the reason why I felt it important to adopt this interview approach with the service user participants, in particular. Schizophrenia as a mental illness is noted for bringing difficulties to service users diagnosed with it. Difficulties such as stigma and symptoms associated with mental illness are known to minimise interest in the sufferers to engage easily with others. For these reasons, it me to carefully work as co-partner with the service user participants, to boost their confidence and motivation to engage in the interviews. Puch & Oancea (2014:148) states

that semi-structured interviews encourage “equal relationships based on trust, enables greater openness and insight” and, as a result, enrich the data.

Considering the data enrichment, the semi-structured interview guide must collect data that reflects the phenomenon under investigation, that is, the validity of the interview guide. Bryman (2012:171) explained validity of a research instrument as the barometer designed to measure a concept that obviously “measures that concept”. In line with this, Saks and Allsop (2013:96) argued that the validity of semi-structured interviews portrays the “richness of the data” gathered. The treasure inherent in the data is gathered using an extensive semi-structured interview guide, and minimising bias to affirm validity (Saks and Allsop, 2013). In addition, collecting a detailed narrative of the phenomenon from the original source supports the validity of the semi-structured interviews (Ahlin, 2019). Appropriateness of the data collection tool in the semi-structured interview design, coupled with the researcher’s skill of facilitating dialogue within the agreed time between the participants and the researcher, validate the data collection process. During the interview, I guided the participant to focus on the topic under discussion, thereby facilitating good interview skills, such as the ability to encourage the flow of conversation and, at the same time, keeping the research participant within the context of the topic being discussed.

Gill et al. (2008) argued that interviews are an appropriate research tool for investigating a phenomenon that is less well known and/or needs to be explored further where participants would be reluctant to discuss in a group context. Thus, in the context of the current research, semi-structured interviews were seen as an appropriate research tool to gauge the perceptions and lived experiences of support among mental health service users and their caregivers.

To conduct the research, I utilized a semi-structured interview guide that consisted of a series of open-ended questions with follow-up probes (See Appendices 12,13 and 14). The questioning was done verbally to gather the necessary data. This approach was in line with the methodology described by Sechhrist and Pravikoff in Parahoo (2014). Such interviews are conversations between the researcher and the research participant in qualitative research, with a view to eliciting relevant information from the research participants to inform the study. Such conversations help the researcher generate information around the experiences and opinions of the participant, for example. They are a useful method to gather in-depth data on the exploration of the phenomenon being interrogated (Say et al., 2013).

All participants were asked the same questions around the major topics and were allowed to discuss their thoughts freely to accentuate the flow of conversation. This approach allows questions to be asked with less emphasis on adherence to the order they are written down

because some of the questions were answered in the participant's comments before the researcher could ask. Participants' comments were probed for clarity and deeper understanding. Each participant's discussion was unique since their experiences were not the same.

Furthermore, semi-structured interviews are the preferred data collection method in the present study, since they offer more freedom and flexibility to interact with participants (Holloway and Wheeler, 2010) – in this case, service users, their caregivers and community mental health nurses.

A pilot study was done in Brodua near the study enclave. After the participants who are residents of Brodua had signed the consent form, they agreed for the researcher to interview them. The interviews were recorded using an audio recorder. Jacob and Furgerson (2012) argue that participants have other commitments and recommend each interview should not exceed 90 minutes. The qualitative interview with service users and caregivers lasted between 45-50 minutes. However, engaging in social conversation with the participants meant that each interview session was about 90 minutes. In the course of interviewing, I made notes.

Semi-structured interviews can be adapted to different participant groups and allow the researcher to probe participants' responses. Adams (2015) suggests that a different semi-structured interview guide is tailored for each participant group. In line with Adams' suggestion, I designed different semi-structured interview guides for each participant group, namely, the service user group, the caregiver group and the professional mental health nurses' group that were working in the community mental health services.

The possibility of probing issues raised by participants offered me the opportunity to ask more questions that were unwritten but kept the subject under discussion in focus. This style of interviewing associated with the semi-structured technique, helped to refine and clarify issues under discussion (Parahoo, 2014). The semi-structured interviews offered the participants the autonomy to narrate their experiences, both past and present, around the support they receive or offer. The participants had the opportunity to revisit some of their responses to clarify them, as I probed the responses. The semi-structured interview guide, which is indicative of questions around the topic, was used successfully to gather the relevant data that met the objectives of this research study, that is, centred around the perceptions and experiences of receiving or giving support.

Other researchers, such as Sternberg and Barry (2011) successfully used the semi-structured interview guide (SSG) to collect in-depth data from participants, when they investigated the health care needs of immigrant mothers. In addition to its primary use, the SSG methodology

has been employed in various healthcare studies to gather qualitative data on the real-life experiences of participants regarding the topic of interest. This approach has been successfully implemented in several studies, including those conducted by Buys et al (2022) DeJonckheere & Vaughn (2019), Kallio *et al.* (2016), Brazier *et al.* (2014), and Larkin *et al.* (2006) – using a semi-structured interview guide to explore participants' perceptions on health. Similar to the other researchers, Paton *et al.* (2014) used the semi-structured interview guide to facilitate conversations around the individual's experience of using therapeutical footwear. In the current research, I utilised SSG in one-to-one interviews with the participants and I found this to be an effective tool to gather data on the participants' lived experiences and to encourage the participants to share their perceptions about the phenomenon under investigation.

The semi-structured interviews, which utilise questions that are indicative of areas of interest, explored participants' understanding of caregiving, their views about the care they received from other family members and professionals, their perceptions of the challenges that the mental health service faces in providing healthcare services and the possible ways to overcome these challenges. The approach is in line with IPA which investigates participants' idiosyncratic lived experiences on support around mental health. Larkin *et al.*, (2006) argued that IPA focuses on individuals when investigating particular experiences, such as the support for mental health service users and their caregivers. As indicated already, the SSG was utilised to encourage the participants to speak more about their life experiences in relation to mental health support. The length of each individual interview was between 60 and 90 minutes with many comfort breaks, to help the participant to maintain good concentration and make the interview sessions less stressful. Consistent with the Interpretive Phenomenological Approach, the participants were informed that there were no right or wrong answers, but that the researcher was interested in learning about their experiences around support in the mental health service in Ghana. After seeking prior consent, the interviews were audio recorded and transcribed for the study. Semi-structured interviews have been used to explore people's experiences and perceptions on their health to affect policy decisions (Couch *et al.*, 2012; Aengibise *et al.*, 2017).

In order to establish an environment conducive to data collection, participants were provided with a comprehensive briefing on the interview process and were informed of the usage of a recorder. It was emphasised that participation was voluntary and that they had the option of withdrawing from the study at any point in time. I also encouraged participants to ask any questions they had both before and during the interview. In order to gather data on the phenomenon under investigation, an approach of semi-structured interviews was adopted, with open-ended questions being asked. This approach allowed participants sufficient time to

articulate their thoughts and provided the opportunity for follow-up questions on emerging ideas. By focusing on general topics, transcriptions from each interview could be compared, thereby enabling the identification of common themes for the study. This helped to generate the content in chapters five and six. Following that chapter seven covered suggested policy implications of the current study.

Open-ended questions are commonly used in semi-structured interview guides. The open-ended interview is considered a gold standard in qualitative research studies (Streubert and Carpenter, 2011). Zander et al., (2015) adopted open-ended questions in their study to encourage discussion on chronic pain. Boyle et al., (2005) asserted that open-ended questions offered the participants the opportunity to talk more, rather than resigning to 'yes or 'no' answers, and also to encourage listening and summarising conversations which contribute to developing person-centred interviews. Adopting an open-ended questioning style, which is a usual characteristic of qualitative research methods, in this case, the semi-structured interview format (Dicicco-Bloom & Crabtree, 2006; Sibeko et al., 2016), the current study explored the participants' perceptions on the topic. The questions probed the service users and their caregivers' knowledge and understanding of support; explored their experiences of support from family members and the mental health service which provides treatment for the community service users diagnosed with schizophrenia. I posed similar questions to the mental health nurses recruited for the study. The open-ended questions also helped to explore challenges that the mental health service provider faces in the delivery of interventions to the community service users, as well as suggesting ideas to improve service delivery. The open-ended questions offered the participants the opportunity to respond in their own way and in their own words. For example, one of the research objectives is: "To investigate support for people diagnosed with schizophrenia from the perspectives of individuals with the diagnosis, their caregivers, and the professional nurses.", and in the interviews, the participants were asked questions such as "Can you tell me about your experiences of support from other members of your family?" This approach of questioning permits the emergence of new ideas since participants are free to express their thoughts, with less restriction on the quantum of information they volunteer in the interview. It is argued that open-ended questions encourage the generation of new ideas, but closed-ended questions, as used in structured interviews, place limitations on the amount of information participants can produce (Tappen, 2023; Hyman & Sierra, 2016). In the present research, open-ended questions in the qualitative interviews were appropriate for participants to share their lived experiences of support in mental healthcare.

Open-ended questions also enable active listening, non-judgmental stance, ability to show empathy, and utilizing language that is intelligible (Hyman & Sierra, 2016; United Kingdom

Nursing and Midwifery Council (NMC), 2015), which were adopted during the interviewing process. Whiting (2008) argues that 'prompt' questions assist the interviewer to maintain the focus and flow of the data gathering with the participants. Prompts are used to gather more information where participants' responses are scanty. In line with Whiting (2008), this study used prompts to encourage participants to elaborate on their responses. This gives more depth and richness to the data gathering. For example, 'You mentioned that this is becoming serious. Can you tell me what you mean by this is becoming serious?' 'Tell me what the problem was' and 'How often do you get professional visitation?' Participants were at liberty to stretch the narration of their stories. I paraphrased some responses during the interviews and asked follow-up questions as suggested by Kallio et al. (2016). In sum, I asked subsidiary questions as prompts to motivate the participants to shed more light on their responses or guide them to return to the key topic if they digressed. This style of interviewing was applauded as it helped the researcher to engineer deeper knowledge of the research phenomenon (Ryan et al., 2009).

The semi-structured interview guide used for this study had four broad questions directing the study. The questions begun with, for example, "What did they say to you", and "Tell me about..." which favoured detailed responses and stories (Baumbusch, 2010; Ryan et al., 2009). In this current study, each interview started with the appeal to engage in conversations around support. This made participants say something about support they have received from others. In addition, I asked about the meaning of support and the type of support available to them. I also asked about the support received from family members, whether this support was useful or not, and the gap in support that participants perceived from family members. Another set of questions explored the support received from the professionals as well as the challenges that confronted the professional service providers.

The conversations helped gather data to meet the principal aim of the research study, and it enabled me to gauge the perceptions of the participants of this study and their meanings around support in mental health.

After each main interview, I discussed the audio recording with the participants. The participants were allowed to comment about their thoughts and feelings after the interview. They all gave positive feedback. All the service user participants stated that they had not been engaged in detailed interviews of this kind before.

Streubert and Carpenter (2011) and Wood and Ross-Kerr (2011) recommend verbatim transcriptions from tape recordings. The transcriptions produced followed the

recommendation and added handwritten notes to the transcripts for comprehensive description. The audio recordings were transcribed for each participant. As a researcher, I arranged for follow up meetings with each participant in their homes to discuss their interview transcripts with them individually. This approach provided participants with an opportunity to see a transcript of their discussions to verify and/or expand their comments about the phenomenon being investigated.

Streubert and Carpenter (2011) suggest the storage of qualitative data on computers. Conforming to the suggestion, the audio recordings were transferred from the audio recorder to a password-locked computer for safe keeping and retrievable only using the password generated by and known to only me. Also, the transcripts bearing pseudonyms of participants were saved in the same manner to protect the identity of study participants.

#### **4.8: Piloting of the Study**

**Lacey** (2015) recommends piloting the study before commencing the major research project. Conducting a pilot study is a critical step in the research process as it involves testing the research design, data collection methods, and instruments (Marufu, 2022) on a smaller scale before the full study is undertaken. This phase helps to identify potential issues, such as ambiguous questions, logistical challenges, or unforeseen variables, and allows the researcher to refine the study design accordingly. Piloting the work may help to address 'uncertainties' about the study (Polit and Beck, 2017, p.623). The rationale for piloting a study is to identify parts of the main research that may encounter difficulties such as the recruitment of interviewees, 'clarity of interview schedules', whether a piece of equipment (e.g. an audio recorder) works well, and the appropriateness of the interview duration (Lacey, 2015, p.26; van Teijlingen and Hundley, 2001). Thabane et al. (2010) argue that the rationale for a pilot study includes improving the process, resources, and management of the main research. Van Teijlingen and Hundley (2001) argue that piloting a study may offer the opportunity to identify the local politics that may impact on the research process. Once the source of any hindrance(s) to the research process is identified, the researcher can negotiate with the relevant influential opinion leaders in the research catchment area to support the successful completion of the data collection.

In the context of this research, four people who indicated their willingness to participate in the study were considered for piloting the study. These participants were the initial four interviewees selected for piloting the semi-structured interview guide. In qualitative research, the emphasis is on the quality of data to offer insight into the participants' experiences of

support in mental health, it is not the quantity of the data (Smith et al., 2012). Therefore, purposively selecting a small sample size to achieve the research aim and objectives is consistent with IPA (Smith et al., 2012; Streubert and Carpenter, 2011). The four interviewees were purposively considered to ensure gender balance in both service user and caregiver groups. Two community service users (male and female in their 40s) with a diagnosis of schizophrenia and two family members (father in his 50s and mother in her 40s) of service users were included in the pilot study. All the four participants were literate, and they met the inclusion criteria of the study. My interest was to ascertain from the answers provided by the four participants, the clarity of questions asked before embarking on the main research. In light of the answers gathered from the interviews, the interview guides (an interview guide for service users, and another for caregivers) were streamlined to capture the main and relevant data for the study. The study was also piloted to enable me as the researcher to improve on interviewing skills and the flow of conversation.

The second stage was to discuss the participant information sheet (PIS) with the participants. I went through the PIS with the participants individually and they were allowed at least 48 hours to think about the study. I met the participants as agreed and discussed the PIS into detail. I checked participants' understanding of the content of the PIS on all occasions when it was discussed. Having shown their understanding of the study demands on them, the consent form was also discussed with the individual participants following their agreement to participate in the study. As part of the discussion, I made the participants aware that confidentiality and anonymity might be broken if their conversations revealed that anyone was at risk. The participants were allowed time to ask questions on all occasions. Subsequent to the agreement to be interviewed, each participant was asked to sign two copies of the consent form. The participants kept a copy of the signed consent form and I kept the other copy. Meeting participants individually was to provide an environment that ensures privacy. I always requested to speak with the participant alone in their own home and ensured the meeting was free from unwarranted intrusion. This stems from an assumption that people would rather keep some information about themselves private. The interviews focused on gathering data about the service user's family life and issues around a mental health condition, which is potentially socially stigmatising. Therefore, it would be preferable to safeguard participants in this manner.

Following the pilot study, participants signed the consent form, I scheduled individual interviews with each of them. The interviews were recorded using an audio recorder. Jacob and Furgerson (2012) argue that participants have other commitments and recommend each interview should not exceed 90 minutes. The qualitative interview with service users and

caregivers lasted between 45-50 minutes. Adding social conversation with participants, each interview session was about 90 minutes. In the course of interviewing, I made notes.

Atkinson and McNamara (2017) and Jacob and Ferguson (2012) recommend that researchers build rapport with participants for better responses. Prior to engaging in interviews, I had established good relationships with participants and maintained this throughout the sessions. Smith et al., (2012) propose an in-depth interview that uses research participant engagement to explore a phenomenon in a meaningful way that enables the participant to share their unique experiences. Using the semi-structured interview guide (SSG), each participant and I engaged meaningfully in interview sessions, as a shared engagement in IPA (Atkinson and McNamara, 2017) to generate data for achieving the research aim and objectives. All participants were asked the same questions around the major topics and were allowed to discuss their thoughts freely to accentuate the flow of conversation. This approach allowed questions to be asked with less emphasis on adherence to the order they were written down because some of the questions were answered in the participant's comments before I could ask. Participants' comments were probed for clarity and deeper understanding. Each participant's discussion was unique since their experiences were not the same.

#### **4.9: Recording the Interview**

Conducting hermeneutic phenomenological research, the rules about taping the interview were established during the consent signing stage. At the beginning of each interview, the participant was reminded about the need for their interviews to be recorded as discussed during the recruitment stage and covered on the participant information sheet. The participants were reminded of the importance of recording their story as evidence of being interviewed, and for the researcher to rely on and transcribe their thoughts as they have presented it. Therefore, the tape or digital recorder is to help the researcher to record the participant's story. Moreover, using the tape recorder in interviews in hermeneutic phenomenological research, is to provide the evidence of the interviews which are the recorded stories. The recorded stories, therefore, become artefacts (Bauer in Bauer and George, 2009; Cohen, Kahn and Steeves, 2000) in the qualitative research study. In modern times, the audio-tape recorder is a preferred device in recording interview sessions between the participant and the researcher (Bryman, 2012) also digital recorders latterly.

The outcome of the interaction between the individual participant and I generated the data for this study. The interview sessions as aforementioned remain important to gather the data where real story telling occurs between the participant and the researcher.

Furthermore, the audio tape recorder was used in the current study because it helped me to provide a relatively precise representation of the data for analysis. The audio tape recorder remains the most common device and a way of recording interviews. The device helped to free the interviewer to focus on the topic and the dynamics of the interview (Brinkmann and Kvale, 2009, 2015). Since qualitative research uses many approaches, in recording data, the researcher used note taking as part of the techniques of recording the interviews. Note taking helped the researcher to jot down the highlights of the interviews, and to note things said that needed follow up questions for clarification. The researcher embarked on transcription following the interviewing process.

#### **4.10: Analytic Process: Transcribing interviews**

Overall, this study collected 37 recordings of interviews between the individual participants and the researcher. These 37 recordings were transcribed by the researcher. 15 out of 37 interviews were in a widely spoken local language called Twi which is also known as Akan. Considering that Akan (with Twi as language) is spoken across the country and in the research enclave, some research participants' chose to speak Twi in their interviews so as to allow them the freedom to express themselves fluently. This accentuated the participant's right to choose. Moreover, I am fluent in Twi and undertook the translation. The translated transcription went through back-translation using independent translators to ensure accuracy in the transcription. Back translation is fully discussed in the next section.

To guarantee the precision of the participants' words, I diligently listened to all the interviews no less than four times. Although it may have elongated the time it took to transcribe the audio recordings, it proved advantageous in capturing every detail and identifying potential themes during the analysis phase. It's worth noting that many researchers consider the transcription stage as the genesis of the analysis process. For example, Bailey (2008, p.129) states:

“Transcription involves close observation of data through repeated careful listening (and/or watching), and this is an important first step in data analysis. This familiarity with data and attention to what is actually there rather than what is expected can facilitate realisations or ideas which emerge during analysis.”

Moreover, Kvale and Brinkman (2009, p. 180) note that transcribing interviews from an oral to a written mode, structuring the interview conversations in a form amendable to closer analysis and is in it.

In Cohen et al., (2011), it is argued that transcriptions offer detailed and exact representation of the data collected and the data are based on the interview recorded in verbatim.

Transcribing the interviews offered the chance to become more intimately acquainted with the data. Additionally, transcribing the interviews allowed for the early identification of emerging themes, affording me the opportunity to colour-code the themes as they emerged and provide descriptive commentary throughout the process.

I made corrections to my transcripts as I noted some words were omitted and made understanding unclear. As I went over the transcripts and the recordings, I identified some omissions such as articles and these were inserted, and names of places and certain individuals identified in the interview were reviewed for confidentiality (pseudonyms were used) and to make the stories complete.

In the process of verifying accuracy of the transcripts, I played back all the interviews again at the time of reading over the transcripts to ensure the transcripts were a replica of the audio recordings. Also, during the last reading of the transcripts, a few corrections were made to ensure that the names of places were replaced with a pseudonym. This approach was applied to all the transcripts before exporting them to the software analysis application, NVivo 12.

#### **4.11: Translation and Back Translation of Transcripts**

Translation and back translation of data collection instruments and interview transcripts in health research is not a new phenomenon. In many international studies that require adaptation of the research instrument to suit cultural needs, translation and back translation have been employed to make the instrument relevant. For instance, Ruiz Yanzi et al., (2019) used forward translation and back translation to ensure that the research instrument 'CollaboRATE', originally written in English, was adaptable for a Spanish speaking population. The CollaboRATE is intended for shared decision-making in health matters and was translated to ensure acceptability among the Spanish speaking study population.

Back translation is the approach to re-translating the content of a previously translated document to its original source (Chen & Boore, 2009). In this study, the semi-structured interview guide was translated from English into Twi and the version was re-translated to English. Moreover, transcripts were translated from Twi to English and English to Twi.

The forward translation and back translation for this study had a complex approach as expounded below.

In this study, the local ethics committee required a copy of the interview schedule in a chosen Ghanaian local language. I arranged for the semi-structured interview guide to be translated into Twi and it was attached to the ethics application before submission for consideration. The semi-structured interview guide was translated by a native speaker of Twi who was a graduate student of one of the universities in Ghana. The Twi version was given to another native Twi speaker who teaches English in a secondary school for back translation. I compared the new English version with the original English version. There were slight changes in wording, but the ideas remained the same. For example, in the original version, a question such as, “what type of support did they talk about?” was phrased in the new version as, “What type of help did you and the other person discuss?”. So, in the new version, the word ‘help’ was used in place of ‘support’, and ‘discuss’ was used in place of ‘talk about’. The changes were not major, it was more of synonym usage. The Twi version of the semi-structured interview guide became especially useful when some participants chose to speak Twi, although they could speak English well. Many participants felt that they lived in their country, felt comfortable and preferred speaking Twi (a Ghanaian language). A total of 15 participants expressed themselves in Twi.

While Ghana is a country with a diverse range of languages, the primary languages spoken in the study enclave are Twi, Ga and English. Participants opting to speak Twi allows for a fair representation of their experiences. It is crucial to minimise any inequalities in data collection and encourage active participation from the participants. Thus, allowing the participants to express their views in their preferred language, in which they are fluent and comfortable, is of equal importance (Kebede *et al.*, 2020; Hyatt *et al.*, 2017).

In the present study, the participants' choice of using Twi to share their stories was acknowledged and allowed as it was in line with their autonomy (Koulouriotis, 2011). Engaging service users whose mental illness has a negative impact on them and their caregivers, means that they need encouragement to participate for their voices to be heard. Therefore, the responsibility lay with me as the researcher to ensure that barriers that limit the participation of interviewees are removed or minimised to the barest minimum. In limiting barriers of engagement between the researcher and the participants, I sought to provide a conducive atmosphere that made the participants feel comfortable to interact and volunteer information to inform the study. Beyleveld and Brownsword (2015) reiterated that the researcher should not decide for the interviewee. Therefore, the participant's choice of interacting in a language they are fluent in during the research study is permissible.

Eremenco, Cella and Arnold (2005) and Fregnani *et al.* (2017; Duffey *et al.*, 2022) describe the translations and back translations of the research instrument as one stage and it is pre-

tested for acceptability. I adopted this approach when the semi-structured interview guide was first translated by the graduate student. There is no Twi word for “schizophrenia.” However, there is a generic word for mental disorder in Twi and it is referred to as “dam” (to wit madness). The Twi version of the interview guide was given to a mental health nurse in Ghana to translate from Twi back to the original version (that is English). The new translation bore semblance with the Twi version. The Twi version was tested on two people (one service user and one caregiver) to ascertain comprehension and applicability of the semi-structured interview guide for both the service user and the caregiver groups.

The translation and back-translation followed several steps to ensure understanding, and accuracy of the transcripts. This study followed Fregnani *et al.*'s (2017) two stage approach (translation and back-translation to the original language that the instrument was designed) in adopting the research instrument (SSG). In this study, the Twi interviews were first translated into English by the researcher. The researcher handed the translated transcripts to three different Twi native speakers to translate back into Twi. After the three translators had individually translated back into Twi, the researcher noted that though they agreed on the main ideas and the import of their translation was clear, one of the translators produced short transcripts – this occurred where the participant repeated a sentence in another stage of the conversation and the repetition was not considered. The other two translators offered detailed translation which was close to my initial translation. See appendices 16 and 17 for the two diagrams of back-translation, one for the semi-structured interview guide and the other for transcription.

#### **4.12: Stages of back-translation of Semi-structured Guide**

As stated earlier, the back translation followed the steps advocated by Fregnani *et al.* (2017). See appendices 16 and 17. Appendix 16 shows the process of back translation of the semi-structured interview guide. This was a requirement for the Ghana Health Service Ethical Review Committee application. A handwritten copy was produced and attached to the local ethics application form. Appendix 17 describes the back translation process for the 15 transcriptions for this research study.

One of the translators was hired to translate all the 15 Twi interviews into English transcripts. Another was hired to translate the 15 transcripts into Twi to verify their semblance. I compared all the translations with my own initial translated transcripts and found that all the translations were very close. All these translators were graduates and health workers who have experience in research and translation from Twi into English. I played back all the interviews again when

reading over the transcripts for accuracy and correction. Checking for accuracy, I compared each transcript with the audio recording and made all the necessary corrections. After checking for accuracy, I accepted the translated transcripts for inclusion in the data analysis. Eight of the 15 interviews were from caregivers who spoke Twi during the interview. The remaining seven of the 15 interviews were service users who spoke Twi.

In sum, all the 15 transcripts, word -processed data, were given to a trusted health researcher for back translation. Back translation was necessary because it helped to assess accuracy of the 15 interviews that were translated from Twi to English. The rationale for employing translation and back translation was to ensure the Twi version of the semi-structured interview guide was equivalent (in text) to the original semi-structured interview guide. Moreover, the translated interview transcripts ensured that the willing participants' request to participate in their language was met in accordance with the local ethical consideration.

#### **4.13: Researcher's Role in Data Collection**

Throughout the research process, as the researcher, I fully engaged in the interview transcripts that were co-created with the respondents. These transcripts were the primary source of data for this study.

I deeply analysed the data and immersed himself in the participants' stories. I co-produced the analysis of the data with the participants of this research. My approach to data analysis was challenged through academic supervision, which helped refine the analysis. To achieve this, I used a double hermeneutic phenomenological approach. This approach involved creating a two-way relationship between the participants and me and required frequently checking back with the participants to ensure the transcripts reflected the views that they had expressed individually.

By adopting this approach, the participants were given the opportunity to make sense of their world, and I gained valuable insight into their experiences. To ensure the research was unbiased, I put aside my personal beliefs and experiences as a mental health nurse practitioner, which could have influenced the research and its outcomes.

I transcribed oral interviews and had the Twi interviews back translated as discussed in Section 4.11 (Translation and Back Translation of Transcripts) and identified themes by carefully reviewing each transcription as guided by Section 4.15. Through interpretative research, I reflected on each interview to clarify the themes. Consequently, the study's themes

were derived solely from the data gathered during the interviews. The themes are presented in Chapter 5 of this study.

#### **4.14: Qualitative Data Analysis**

The data analysis explores the key steps taken to analyse the data collected from varied sources to inform this study and draw out the key findings. Constructing the data which is the field text through interviews and interpreting the data is a complex process (Hemminger, 2018). The data analysis of the qualitative research process is demanding and requires the researcher to immerse themselves in the process and pay attention to all the parts of the process to draw out robust findings (Glaser & Strauss, 1967).

Qualitative data analysis is considered an iterative process whereby the researcher moves back and forth between data collection and analysis (Clark and Braun, 2023; Morgan and Nica, 2020). In describing the phenomenological analysis of data, it is argued that:

*“...analysis begins with data collection. As the researcher begins constructing the field text through interviews and observations, the researcher cannot help but begin reading this text, and hence analysing and interpreting its meaning”*  
(Cohen et al., 2017: 71).

Bogdan and Bilen (1982) referred to data analysis in qualitative research as the process of organising and arranging the interview transcripts, observation, notes, or other non-textual materials that the researcher gathers to increase understanding of the research phenomenon. In this study, data analysis was based on interview transcripts from three groups, namely, service users, caregivers, and mental health nurses. The process of analysing qualitative data requires coding (Wong, 2008). The coding process helps make sense of the substantial proportion of data by truncating the quantity of raw information, followed by identifying significant patterns, making meaning from data, and then building coherent evidence (Patton, 2015).

Data transcription is a time-consuming process (Clark and Braun, 2023), and as the researcher, I spent many days transcribing the audio recorded interviews. Analysis of data helps to answer the research study question and objectives and draw implicit

meanings of the interviews (Ngulube, 2015). This study employed the thematic analysis approach to qualitative data analysis (Braun and Clarke, 2006). Mason (2000) advocated for the use of themes in an attempt to analyse qualitative data. The themes are drawn from the analysis of the data (Dawadi, 2020; Egbunike *et al.*, 2010). The current research also adopted thematic analysis on the basis of exploring the research phenomenon. For this study, it has been determined that a thematic and phenomenological analysis is the most suitable approach. Thematic analysis is discussed next followed by phenomenological analysis.

According to Braun and Clarke (2006) and Naeem *et al.* (2023), thematic analysis is made up of six stages:

- familiarisation with the data
- generating initial codes
- searching for themes among the codes
- reviewing themes
- defining and naming themes and
- producing the final report.

Silverman (2011) however only mentioned the first five steps as the main steps for thematic analysis.

Familiarisation of the data involves reading the transcripts several times and writing down initial comments and ideas (Silverman, 2011; Creswell, 2014). Once the researcher is familiarised with the data, initial codes can be generated. Saks and Allsopp (2013), agree that thematic analysis is preferable when analysing unstructured or semi-structured data. The emphasis is on coding the similarities in meaning rather than common phrases as research participants may say something similar but in different expressions. After identifying initial codes, these were grouped to create potential themes. The next stages involved the reviewing and refining of the identified themes (Saks and Allsopp 2013; Silverman, 2011; Creswell, 2014), to develop core themes and related sub-themes.

Whereas Braun and Clark (2006) describe a six-stage model, Smith *et al.* (2012) describe a seven-stage model used in the current study. According to Van Manen (2016), a central stage of thematic analysis captures the themes that are woven into

the evolving meanings and imagery of the work. This methodology is grounded in phenomenological analysis, which involves uncovering how individuals in a specific context comprehend a particular phenomenon. The extent of my engagement with the participants' texts is recognised by the process of thoroughly immersing myself in the data and deliberately suspending preconceived notions.

#### **4.15: Data Analysis in the Current Research**

In this section, I reflect on the qualitative data that were collected through my face-to-face, in-depth interviews. From my experience in research seminars and through academic supervisions, I became aware that the process of data collection, analysis and producing the research report are interrelated parts and do not occur in clearly distinct and progressive stages. I was also aware that the process of data analysis is not straight forward, it is an iterative process (Clark and Braun, 2023). Notwithstanding, the stages of analysis are described to clarify actions that were carried out. The analysis of the interview transcripts followed the general steps of thematic analysis and Interpretative Phenomenological Analysis depicted by Smith et al (2012).

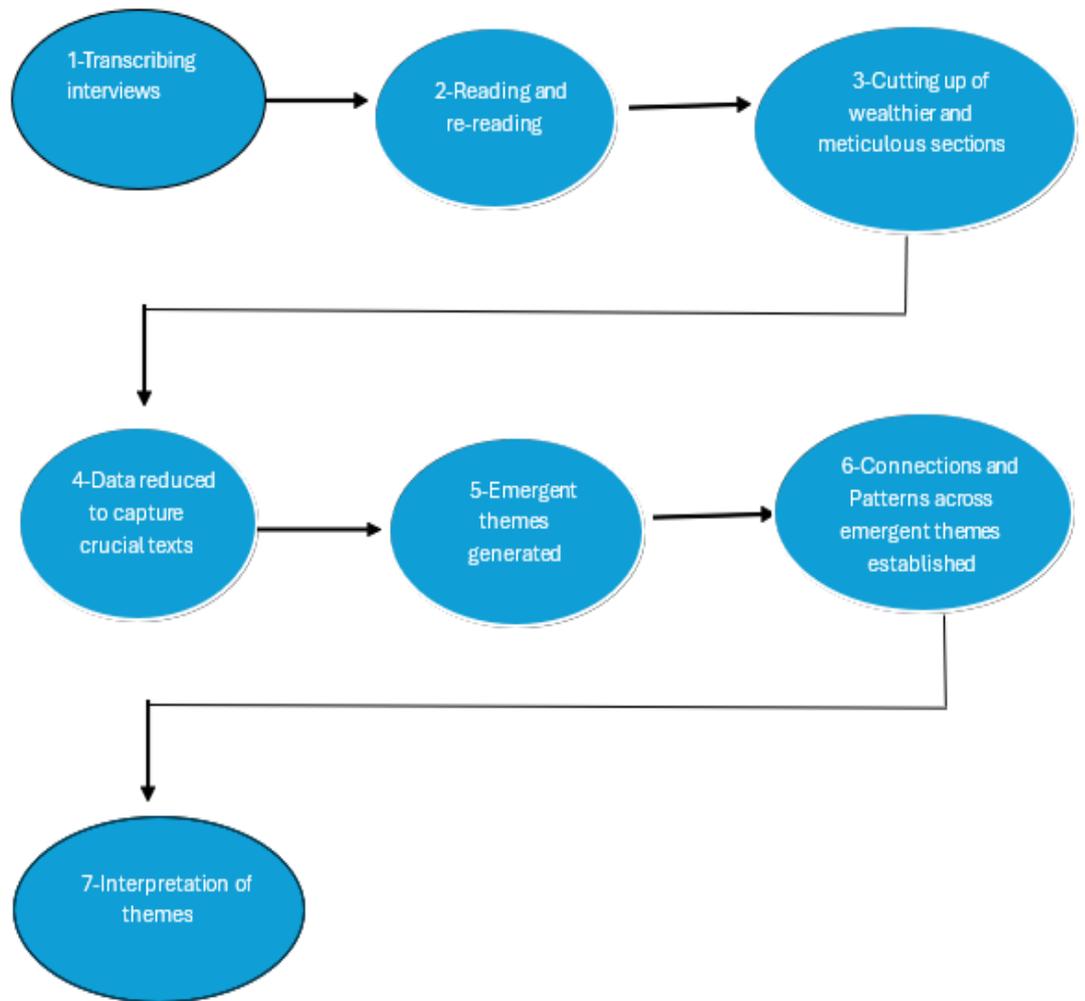


Figure 4. 2: Researcher's adaptation of Smith et al (2012) IPA data analysis

Figure 4.2 describes the approach (steps) used in the analysis of the data for this study. The initial step in the analysis entailed transcribing the interviews verbatim. This was followed by a deep dive into the primary data through careful review and immersion. By thoroughly reading and analysing the accounts, I was able to gain a deeper understanding of the data. This thorough approach included cross-checking the transcription against the audio recordings to ensure accurate representation of the participants' words in the analysis. By reviewing the data multiple times, I was able to formulate a comprehensive interview framework in my mind, which aided me in comprehending how the accounts intertwined different elements of the interview. It also involved annotating the text with a view to organising and developing themes. This process fostered a sense of understanding and trust between the narratives, revealing and emphasising the rich and distinct segments while identifying any discrepancies. The methodology entailed physical separation of the data using scissors to cut up parts of the printed words from the same data. A word processor was utilised to highlight pertinent

segments of the data, thereby reducing the volume of information for more thorough analysis (Charlick *et al.*, 2015).

In the third phase, a thorough examination of my descriptive comments entailed a concentrated effort to unpack and analyse the contents enumerated by the respondents with respect to the subject matter at hand. In this stage, I paid more attention to the text, taking care to explore the specific languages utilized by the respondents.

Additionally, in order to streamline the analysis process, I carefully analyzed the connections, interrelationships, and patterns within the transcripts, following the methodology outlined by Braun and Clarke (2006) and Smith *et al.* (2012). It was essential to distill the information into succinct and meaningful statements, focusing on the most important aspects of the text. Through this process, I identified themes that captured the unique perspectives and narratives of the respondents, as well as my own descriptions of their accounts.

In the fourth phase, I utilised the technique of 'abstraction and integration' to identify patterns among emergent themes. By examining the interrelationships between these themes, I was able to group together similar perspectives and assign them a descriptive label. I provided an interpretation of the themes discovered, while comparing and contrasting my findings.

During the fifth phase, I transitioned to a different transcript and attempted to isolate and categorise themes from the preceding phases. I adopted an unbiased approach to ensure that each new case was evaluated on its unique merits and not influenced by previous analysis.

During the sixth phase of my analysis, I looked for patterns across cases. I observed common higher-order qualities among cases, while also noting of unique and individual occurrences. In the subsequent seventh phase, I delved deeper into the data to derive more comprehensive and meaningful interpretations.

The entire exercise could not have been completed without using manual techniques and a computer assisted programme (NVivo), which are briefly discussed below.

#### **4.16: Coding in Interpretative Phenomenological Analysis**

Coding is a very important activity in the data analysis stage. Coding involves the merging of textual data into chunks, examining the data similarities and differences, and putting together conceptually and empirically similar data in the respective nodes. (Wickham and Woods, 2005). Coding helps to analyse qualitative research materials such as interview transcripts

considered for this research study. Bryman (2012) describes this stage as the genesis for actual analysis of qualitative studies. Coding helps in developing themes from the narratives of the participants. Coding in this study involved two stages, namely, manual and computer software application using Nvivo 12.

#### **4.16.1: The manual stage**

This stage of coding started with reading and re-reading of the transcripts, coupled with annotating the text with the view to organising and developing themes. This stage in the coding process involves initial themes being developed in line with the key issues that emerged from the interview transcript. This was to ensure the initial analysis was data driven (Streubert and Carpenter, 2011) as proposed at the onset of this research study. I wrote emerging themes on pieces of paper segmented and regrouped them based on common ideas/themes.

#### **4.16.2: Qualitative Data Analysis Software (QDS)- NVivo**

Coding starts with the word-processed data (Sinkovics and Alfoldi, 2012), which in this research study is the transcript. The transcripts were imported to the NVivo project file. NVivo is the computer assisted software programme to help analysis of the transcripts.

The recorded transcripts were then analysed following Smith et al's (2012) and Cohen, Kahn and Steeves' (2000) method for Interpretative Phenomenological Analysis. The transcripts were read and re-read many times, and themes were formulated and coded. The rate of coding each item and the number of times each theme was coded alone was not considered to be meaningful. The codes were reviewed many times, and emerging themes/cross cutting themes across the data set were gathered. This method enhances the pragmatic approach towards clustering similar ideas to form a theme. The themes are the meaning units constructed from the data (Streubert and Carpenter, 2011). The computer software package NVivo 12 was used to boost data analysis. NVivo does not substitute the manual approach of getting familiar with the data, coding and generating themes, but boosts the analysis (Saks and Allsopp, 2013).

The decision for me to start familiarising with the data, coding and generating themes prior to using the NVivo 12 software application was necessary to organise the data in a meaningful and interpretable form.

The merits of using NVivo encompassed efficiency and transparency of the data analysis process, leaving an ‘audit trail’ for the analysis (Houghton et al., 2017), which was relevant for discussions in academic supervisions. The academic supervisions served as triangulating the research findings to provide credibility to findings and conclusions drawn.

The process of analysing data with NVivo included importation of the word-processed transcripts which bore the pseudonyms of participants. The process also included developing and improving initial themes (called ‘nodes’ in NVivo) that had emerged through further re-reading of the transcripts. The essence of re-reading was to distil and vet whether the data supports emerging themes, and the research aim and objectives.

After reviewing the emerging data, I refined the themes for the next stage. At this stage, I checked for connections and patterns between the emerging data, refined, defined, and named themes (Braun and Clarke, 2006; Silverman 2011; Saks and Allsopp 2013; Creswell 2014; Smith et al., 2012).

The data analysis required careful review of transcripts, audio recordings, and revisions to the coding system. The wealth of existing literature provided guidance to support the development of emergent themes and their description. To provide an example of the emergent themes and their descriptions, I was guided by Luff & Kanyal’s (2015) to produce the table below. Table 4.1 below depicts a sample of the coding process and the theme (and sub-themes) development.

**Table 4. 1: Sample of a list of themes with related descriptions and examples**

Themes	Description	Example from data
Impact of illness: <ul style="list-style-type: none"> <li>- Loneliness</li> <li>- Financial cost</li> <li>- Abandonment</li> </ul>	Perception of loneliness	“I don’t go to meetings regularly and sometimes I don’t go to church... I don’t get time to go to church but I know without God I can’t survive. ... testimonies about what God has done through me. Mad men got healed...I have all the pictures here... I haven’t been able

	<p>Perception of cost of treatment →→→</p> <p>Perception of abandonment →→→</p>	<p>to go to church regularly but God knows. ... the Bible tells us not to neglect our fellowship but it is the problem I have which prevents me from attending church.” (Lazarus: Caregiver)</p> <p>“Fees charged at the hospital are very high. Mental health patients are not on National Health Insurance Scheme...of patients walking in the streets. ... they can't pay the hospital bills. Such patients don't have any family member visiting them. Some families are fed up with their patients, so when they are able to get some money to send them away to the hospital then that is the way to end part of their problems.” (Emmanuel, Caregiver)</p>
Need for improving record keeping	Perception of poor record keeping	“The nurses are visiting us here and giving the injection. Would it be prudent to have a book to record their visitations and people they have given injections each day and inform the hospital? My

		<p>observation is that they come to inject the people but there is no record.” (Lazarus- participant caregiver)</p>
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### Summary and conclusion

The methods section indicates activities I engaged in to gather data for this research study, and the rationale for choosing them. The credibility of this study is hearing the voices of the service users, caregivers and the clinical staff in the enclave, and, without the participation of these three groups, this study would not have come to fruition. I am grateful to these participants for their time and information they shared to inform the data for this study. This chapter also covered aspects of rationale for the study, details of the locus of the research, as well as sampling strategy, which was introduced at the start.

My role in managing activities in this study, my beliefs and experiences as a mental health nurse practitioner, might have influenced the study. Thus, the measures taken to reduce the impact of my beliefs on the outcome and findings of the current study have also been clarified. For example, allowing the data to inform the study and drawing meanings from the available data to formulate themes, demonstrates my belief in amplifying the voices of the participants to encourage improvement in the current situation of the community mental health service in Ghana. The next chapter will present the findings and analysis in relation to the overall research question, aims and objectives of this research study.

## **CHAPTER FIVE: FINDINGS FROM SERVICE USERS, CAREGIVERS AND NURSES**

### **5.1: Introduction**

This chapter reports on the findings of the study, that is the findings of the primary study. The chapter first presents a brief discussion of the demographic characteristics of the participants. This is then followed by a presentation of the themes generated from their interviews. The generation of the themes involved a careful reviewing of the qualitative data collected for this research study, followed by systematically transcribing participant interviews. The transcripts provided a rich text for examination that helped build an understanding of the phenomenon for this research. Through the analysis of the data, this research made sense of the data by reducing the magnitude of the raw information, then explicating significant patterns, and pulling meaning from data to construct a coherent conglomerate of evidence (Patton 2015), which were the themes.

### **5.2: Demographic characteristics- Participants of this study**

The various participant groups are described in this chapter as part of the analysis to reveal the different groups I interviewed in this study. As mentioned in Chapter 4, all the participants were given pseudonyms that are represented in Table 5.1, 5.2, and 5.3.

#### **5.2.1: Service User Participants**

There were 10 service user participants who engaged in the research. The participants constituted five females and five males. In this chapter, the experiences of the service users which represent part of the findings were drawn to inform the themes in this chapter. The demographic characteristics of the service user participants are depicted in table 5.1 below.

The first column of Table 5.1, 5.2, and 5.3 shows the pseudonym of each participant. The pseudonym was identified at the time of collecting data from the research participants. Before commencing the in-depth interviews, all participants engaged in a discussion to determine the pseudonym each wanted to use. This decision-making process reflected a democratic approach to data collection. Initially, I proposed using number codes, such as "Service User 1," but the participants expressed a preference for proper nouns. Drawing from prior

experience in collecting data from service users, I similarly allowed caregiver and nurse participants to promptly select their own proper nouns.

I sought to represent a gender balance in this group and was successful in obtaining an equal number for both sexes.

**Table 5. 1: Demographic characteristics of service user (SU) participants**

<b>PSEUDONYM</b>	<b>AGE</b>	<b>GENDER</b>	<b>EDUCATION</b>	<b>EMPLOYMENT</b>
<b>Agnes</b>	41-50	Female	Basic	Self-employed
<b>Ago</b>	51-60	Male	Masters	Unemployed
<b>Danso</b>	21-30	Male	Basic	Self-employed
<b>Gifty</b>	41-50	Female	Basic	Self-employed
<b>Hilda</b>	51-60	Female	Basic	Unemployed
<b>Maya</b>	21-30	Female	Secondary	Self-employed
<b>Mensah</b>	41-50	Male	Basic	Self-employed
<b>Sarah</b>	41-50	Female	Basic	Unemployed
<b>Sulay</b>	41-50	Male	Diploma	Unemployed
<b>Thomas</b>	31-40	Male	Secondary	Unemployed

Table 5.1 depicts the demographic characteristics of the participants who received mental healthcare services. Inclusion of service users was a crucial aspect of this study since it partly focused on mental healthcare delivery to this population. In light of the significance of service users in the study, their involvement was deemed necessary to derive meaningful findings.

The service user group for the mental health service exhibited a variety of unique characteristics, including age, gender, education, and employment status. The participants' ages ranged from 21 to 30 years old. Among them were two individuals, one female and one male, both of whom were self-employed. The female participant had completed secondary education, while the male participant held a certificate for basic-level education.

The other age group was 31-40 years old. There was only one male participant with secondary school certificate and was unemployed.

Within the 41–50-year age range, there were a total of five participants, consisting of two males and three females. Of the female participants, all possessed basic education and were self-employed, except for one who was currently unemployed. As for the male participants, one held a Diploma certificate but was currently unemployed, while the other had basic qualifications and was self-employed.

In the study, two participants within the 51-60 years of age group were both currently not employed. One participant identified as male, and the other as female. The female participant had completed basic education, while the male participant held a second-degree certificate as a graduate.

The next section presents the demographic data of the caregiver group.

### 5.2.2: Caregiver Participants

Apart from the service user group, the study also gathered data from the individual caregivers and Table 5.2 below offers a summary of the characteristics of the caregivers who participated in the study.

**Table 5. 2: Demographic characteristics of caregiver participants**

<b>PSEUDONYM</b>	<b>AGE</b>	<b>GENDER/ RELATIONSHIP TO SERVICE</b>	<b>EDUCATION</b>	<b>EMPLOYMENT</b>
<b>Aba</b>	41-50	Female/ Daughter	Secondary	Unemployed
<b>Alpha</b>	41-50	Male/ Son	Secondary	Employed
<b>Augusta</b>	Up to 20	Female/ Daughter	Secondary	Employed

<b>Banta</b>	31-40	Male/ Brother	Degree (In Tertiary)	Unemployed (Student)
<b>Cecilia</b>	41-50	Female/ Sister-in-law	Basic	Self-employed
<b>Connie</b>	51-60	Female/ Mother	Basic	Self-employed
<b>Dean</b>	31-40	Male/ Son	Secondary	Self-employed
<b>Emmanuel</b>	51-60	Male/ Brother	Secondary	Employed
<b>Esi</b>	51-60	Female/ Mother	Basic	Unemployed
<b>Fabia</b>	51-60	Female/ Mother	Basic	Self-employed
<b>Frieda</b>	41-50	Female/ Sister	Basic	Self-employed
<b>Hannah</b>	51-60	Female/ Partner	Basic	Self-employed
<b>Hazel</b>	41-50	Female/ Auntie	Masters (Tertiary)	Employed
<b>Ishaq</b>	31-40	Male/ Brother	Basic	Self-employed
<b>Lazarus</b>	51-60	Male/ Father	Secondary	Unemployed
<b>Osman</b>	21-30	Male/ Brother	Bachelor's degree (currently in Tertiary)	Unemployed (Student)
<b>Sampa</b>	51-60	Male/ Father	Secondary	Unemployed
<b>Sylvia</b>	51-60	Female/ Mother	Basic	Unemployed
<b>Taylor</b>	51-60	Male/ Father	Secondary	Unemployed

<b>Theresa</b>	31-40	Female/Sister	Secondary	Employed
<b>Zane</b>	31-40	Male/ Brother	Secondary	Self-employed

Table 5.2 depicts 21 caregiver participants who participated and co-produced the data for this research. One participant was a female who was between 18-and 20 years of age, had secondary school certificate and was employed. Another participant was a male and in the range age of 21-30 years old and was studying at the tertiary level, and he is unemployed.

There were five participants in the age range of 31-40 years old. One was a female with a secondary school certificate and was employed. The other four were all males. One out of the four was studying at the tertiary level and was unemployed. Two out of the four males had secondary school certificates and were self-employed, and the other held basic school certificate and was also self-employed.

There were another set of five participants who were in the age range of 41-50 years. There were four females out of the five participants in this group. there was one out of the four women who held secondary degree and was employed. There was another woman with a secondary school certificate and was unemployed. The other women held basic certificate of education and were self-employed. The only man in this age range held secondary school certificate and was self-employed.

In this study, nine individuals between the ages of 51 and 60 were interviewed, with five females and four males in the group. Of the women, one had a basic educational certificate and was currently not employed, while the remaining four were self-employed and had basic school certificates. Conversely, all four men in this age range had completed secondary education. Among them, only one was employed, with the remaining three being unemployed.

The chapter is divided into three sections based on the key themes identified in the service user and caregiver interviews. The key themes in this chapter include:

- (a) perceived meaning of support
- (b) professional support that the service users receive and
- (c) support that the caregivers receive and the appropriateness of it.

The next group of participants for this study to unveil is the staff nurse group, and it is discussed in Section 5.2.3.

### 5.2.3: Staff Nurse Participants

There were six staff nurses who engaged in the research. The participants composed of two female and four male mental health nurses. In this chapter, the findings are drawn from the professional mental health nurse or known as the psychiatric nurse. The demographic characteristics for the nurse participants are depicted in Table 5.3.

The researcher sought gender balance in this group. However, two female staff dropped out because they did not avail themselves for interviewing.

**Table 5. 3: Demographic characteristics of Staff Nurse participants**

<b>PSEUDONYM</b>	<b>AGE (YEARS)</b>	<b>GENDER</b>	<b>EDUCATION</b>	<b>ANNUAL SALARY RANGE IN CEDIS ('000)</b>
<b>Abrafi</b>	<b>31-40</b>	<b>Female</b>	<b>Bachelor's Degree</b>	<b>32-26</b>
<b>Anane</b>	<b>41-50</b>	<b>Male</b>	<b>Diploma</b>	<b>20-24</b>
<b>Ayitey</b>	<b>21-30</b>	<b>Male</b>	<b>Diploma</b>	<b>16-18</b>
<b>Dosu</b>	<b>31-40</b>	<b>Male</b>	<b>Diploma</b>	<b>20-22</b>
<b>Nyarko</b>	<b>41-50</b>	<b>Male</b>	<b>Master's Degree</b>	<b>30-34</b>
<b>Yacoba</b>	<b>41-50</b>	<b>Female</b>	<b>Diploma</b>	<b>18-20</b>

Table 5.3 represents six nurses who participated in producing the data. One participant, a male aged 21-30, held a diploma certificate. In the 31-40 age range, there were two participants: one female with a bachelor's degree and one male with a diploma certificate. The remaining three participants, aged 41-50, included one female and two males. One female and one male held diploma certificates, while the other male had a second-degree, all-in Nursing.

I meticulously transcribed oral interviews and discerned themes through a thorough review of each transcription. Employing interpretive research, I carefully reflected on each interview to

elucidate the identified themes. As a result, the study's themes were exclusively derived from the data collected during the interviews.

### **5.3: Themes**

The findings of this study are presented as themes generated from participants' interviews. The research findings are therefore presented thematically to help readers understand the support provided by the participants in the research study. The key themes and sub-themes identified from the data analysis and theme generation will be supported by quotes from the interview transcripts. In addition, in Chapter 4, this research study made a case to employ IPA in qualitative research design, which was also combined with thematic approach (Silverman, 2024). Thus, the IPA and thematic approach are used to help organise the findings to make them meaningful.

Below are the findings in the form of themes from the data. The themes are each reported accordingly from the perspectives of the various participants, namely, service users, caregivers, and nurses. These key themes encompass:

- (a) the perceived meaning of support for service users
- (b) the nature of professional support for community mental health service users
- (c) the experiences of nurses providing care in the community mental health setting
- (d) the services provided to caregivers and their suitability,
- (e) The challenges facing community mental health services
- (f) recommendations for areas requiring policy planning and support implementation

An important observation from the following findings: (a) the perceived meaning of support for service users and (b) the nature of professional support for community mental health service users, was that, participants tended to merge, account for or even saw some aspects of the two findings as the same or similar (such as emotional, spiritual and counselling), notwithstanding how much I rephrased the question to aid them to distinguish between these aspects in the two findings. For example, participants were able to readily provide their understanding of the meaning of what support was for service users, such as pointing to the forms of support as: general, physical and psychological. However, when they were asked to outline the nature of the professional support provided for community mental health service

users, they still indicated that what they conceptualised as the meaning of support for service users was also noted as what was provided by health professionals (nurses), such as emotional, spiritual, counselling. These views by participants (aspects of findings- a and c - emotional and counselling) therefore need clarification and addressing because they will influence the discussion of the findings and therefore the aim of the study. Therefore, presenting findings as participants indicated, helps to situate participants responses as closely as possible in the wider context to the lived experiences of the participants (van Manen, 2014). As such, in the presentation of the findings these aspects emotional and counselling will not be duplicated. Furthermore, objective (f) offers recommendations for areas requiring policy planning and support implementation, helps to conclude the study, therefore will be discussed in chapter 7- conclusion.

#### **5.4: Theme A- Perceived Meaning of Support for service users**

Participants expressed their understanding of the concept of support service users diagnosed with schizophrenia receive. This perception of support was expressed in many dimensions. Under the main theme of Perceived Meaning of Support for service users, the following subthemes emerged. These are:

(i) general

(ii) physical and

(iii) psychological meanings of support and will be discussed in turn. To aid understanding, a brief explanation of these subthemes is presented below, however, these dimensions will be examined in further detail in the subsequent sections of the chapter.

##### **5.4.1: General View of Support**

General Support: This encompasses diverse forms of assistance and care without being tied to a specific type or method.

The study offered a comprehensive perspective on the notion of support in daily life, which did not center around specific objects for providing or receiving support. Instead, it aimed to evaluate the needs of potential support recipients. It was interesting to note that all participants had a varied understanding of what support meant to them.

## 1. Service users

For example, service users perceived support as:

“Support refers to what someone else gives you to meet your need.” (**Agnes, Service User**).

as “... taking action to stop or reduce someone’s distress.” (**Danso, Male, Service User**)

## 2. Caregivers

Caregivers perceive *support* as the willingness to take meaningful actions:

“I understand support as willingly performing an act that benefits the person receiving it. The one offering that support doesn’t do so under any compulsion. One should not compel any other person to offer support. If you want to help someone, you must know what will benefit them.” (**Theresa, Caregiver**).

“He is not well. So, my understanding of ‘support’ is the contribution others make to help my son recover from his illness.” (**Esi, Caregiver**)

“If someone needs help, you discuss it with them first, find out their needs and give them something to meet the identified need. Taking medication is an example of help that the sick gets. It helps them to get better. When they get better, they can do some work to earn a living.” (**Sylvia, Caregiver**).

## 3. Nurses

Nurses’ perception did not include imprecise view of support. Therefore, this study does not provide examples from nurses in this section.

The broader view suggested that ‘support’ could be perceived from varied angles. It was interesting to note that both service users and caregivers offered such broad interpretations of support, shedding light on their broad understanding of what support entails. It was intriguing to observe how these different participant groups shared a similar general perspective on support, reflecting a communal and inclusive view. However, unlike service users and caregivers, the nurses did not present a general view of support. This contrast suggests that nurses may approach the concept of support from a more specific or

professional standpoint, focusing on aspects of care rather than a broad, overarching interpretation.

The next subtheme looks at another interpretation of support as a concrete item.

#### **5.4.2: Physical Meaning of Support**

Physical Support: This includes practical help such as providing medication, financial aid, employment opportunities, and other material resources that directly impact the well-being of service users.

From the analysis, all participants perceived support as a transaction that involved physical resources. This materialistic concept highlighted the exchange of tangible items from the helper to the recipient, aimed at managing crises and improving the recipient's health and wellbeing during difficult times. The data revealed that all participants viewed physical support as crucial for addressing immediate needs and helping to stabilise situations where individuals faced significant challenges. This understanding of support emphasised the practical, resource-based assistance that was crucial in helping individuals to navigate and overcome crises. The following extracts from participant discussions provide evidence of these perceptions of physical support.

##### **1. Service users**

For example, service users perceived support from tangible items such as:

“...gifts like money that you receive...” **(Mensah, Service user, Male)**

“I think support is about...the medication and how to manage the illness... refers to getting the right medication that reduces the symptoms of the illness. ... getting free medication which, we don't get.” **(Gifty, Service User, Female)**

##### **2. Caregivers**

Caregivers expressed a similar view of support as tangible items as illustrated in the extract below:

“Support may come in various forms... It might come in physical form. The physical form might be financial or using your strength in one or two activities ...and/or physical support.” (**Osman, Male Caregiver**)

“My understanding of support is getting the drugs [medication], ... money.” (**Augusta, Caregiver, Female**)

“Support... can be information, money, food, medicine, or someone keeping an eye on the sick. It is a lot and those I have just said are enough.” (**Fabia, Caregiver, Female**)

“Support can be financial and...medication.” (**Lazarus, Caregiver, Male**)

### **3. Nurses**

Nurses saw physical support in a similar light. They identified similar tangible items as:

“...if you find a patient who is relapsing and the family don't have the money to buy the medication, we buy the medication for them. If the patient has not eaten... We... give them money to buy food to eat immediately... We don't claim back the money we use on the patients from the organisation. ... We are helping our fellow humans in need. I want to repeat, there is no way we can claim such monies and we do it to help them.” (**Yacoba, Female Nurse**).

“The types of support..... I will classify them to include medication, home visits and follow-ups....” (**Nyarko, Male Nurse**)

“... We get them something to eat and help to get them medication.” (**Ayitey, Male Nurse**)

The extracts from the participants identified various tangible items that included medication, money and food. The physical concept emphasises the exchange of tangible items from the helper to the recipient, aimed at managing crises and improving the recipient's health and well-being during difficult times. Participants view physical support as crucial for addressing immediate needs and stabilising situations when individuals face significant challenges. This understanding of support emphasises the practical, resource-based assistance that is crucial in helping individuals navigate and overcome crises.

The observations from the participants demonstrate that their perception of support is synonymous with commodities that are visible to them. The availability of tangible assets,

namely, money, medication, and food are deemed the very basis of support. Basic human needs remain the most relevant factor. Therefore, understanding the various interpretations and uses of physical support offers a better approach to effectively address challenges concerning schizophrenia. It is relevant to organise the tangible items that would improve the mental health of the service users.

### **5.4.3: Psychological meaning of support**

Psychological Support: This comprises emotional and mental support, encompassing counselling, emotional encouragement, and other forms of assistance aimed at enhancing the mental and emotional well-being of service users.

This section identifies different dimensions of psychological support in the pursuit of meanings of support. The individual facets of this type of support are emotional and mental support, counselling, and spiritual support and each will be discussed in turn.

#### **5.4.3a: Emotional Support**

This entails the emotional aspects attached to the understanding of support in managing schizophrenia. This part of the study uncovers the perspectives of service users, caregivers and professional nurses which are evidenced in the semi-structured interviews. The participants perceived support as having emotional underpinnings within the research study enclave. Some affirmations gathered from the interviews are shown below. For example,

##### **1. Service users**

Service users perceived emotional support as:

“I live in our family house with another sister and brother. We all live together as a family. If I have any emotional problem, I discuss it with my sister. Their presence is a form of support. If I was living alone and far away from them, I don’t think I would survive [cope]. The fact that they are around.... I think I get the social support from them.” (**Thomas, Service User**)

“My son... talks with me and makes me feel valuable. When he talks with me, he always reassures me that I will be well. These are important.” (**Agnes, Service User, Female**)

## 2. Caregivers

Caregivers expressed a similar view on emotional support as they opined:

“The nurses are cordial with her. They converse with her. They make her feel welcome. They visit her and converse with her. She doesn’t get anyone to speak with her as the nurses do when she goes to the hospital for review. She gets emotional support from the professionals and that, to me, is enough. They don’t make her feel that she is stigmatised over here in our community... because of her illness as a mental health patient. She’s welcome when they see her....” **(Osman, caregiver, Male)**

“...occasionally and once a while, her sisters, you know that they are also very old. They try to visit her. Even though it isn’t too regular. She is their last born, and because of the love they have for her they come around. The visit is deemed as emotional support.” **(Alpha, Caregiver, Male)**

## 3. Nurses

The nurses offered similar understanding as:

“Support ... is rendering mental health services for those who need them.... those who are mentally ill. This includes giving them support to manage their stressors so that they maintain their emotional wellbeing better...” **(Dosu, Male staff, 31-40)**

They find comfort when they come to us.” **(Ayitey, Male, 21-30yrs old)**

The participants related an aspect of psychological support as emotional support they considered it as valuable. The participants identified family members and healthcare professionals (especially nurses) provided emotional support to improve the wellbeing of the service users and their families. It highlighted a sense of living together and facilitating the discussion of people’s needs. The social milieu provides a platform for sharing important personal issues with others around such individuals. In the community setting, it requires that service users engage with others to talk about their concerns and seek help to deal with those concerns. It helps to reduce the stress of feeling lonely.

### 5.4.3b: Spiritual Support

Another understanding of psychological support the participants gave was spiritual support.

#### 1. Service users

“I have prayed to God for healing. I know that God will heal me. When I go to church, I ask God to help me to stay well and continue with my petty trading so that I can pay for my treatment in future. I am hopeful that God will deal with my enemies and improve my situation. **(Gifty, Service User, Female)**

All my family members and I are Muslims. We say our prayers at home. We go to the mosque and join other Muslims to say our prayers, especially on Fridays. I find this very helpful because when I am in the mosque, the voices don't come. The voices stop. Allah is great to heal me. **(Sulay, Service User, Male)**

#### 2. Caregivers

The caregivers expressed their understanding of spiritual support as an aspect of psychological support. They commented as:

“...In fact, for me to keep her here, it's only by God's grace... I will survive. I am trusting God to heal her. I have prayed for her illness over the years. God is with us, and he will do us well.” **(Lazarus, Caregiver, Male)**

“I can't do anything other than to leave it in the hands of God. God knows why he gave us this sister. I will never question God.” **(Osman, Caregiver, Male)**

#### 3. Nurses

The nurses expressed similar perceptions as given by the service users and caregiver. For example,

“...they believe the illness is a spiritual problem and all they need is to pray for healing, it is not about taking any medication. Such cases must be monitored regularly... It helps other colleagues who visit the patient to be aware of the family's views about the illness and the treatment. It helps the colleagues who will work with the patient in future to be aware of the family's views, and to plan about how to handle the patient and their family.” **(Yacoba, Nurse, Female)**

The participants referenced spiritual support as a source of motivation to cope with their difficult situation. In difficult times, the service users and their caregivers were resigned to the

intervention of a power beyond human reach. They drew on spiritual support to stay positive in anticipation of getting other support that would help them to manage their difficulties. Such a frame of thought is likely to empower them to persevere and continue to live with the negative impact of schizophrenia of their sick relative, and often strained relationships between the sick, the caregiver and the wider community.

The spiritual support suggests that caregivers embrace their humanity by acknowledging and accepting their limitations in providing relevant support to service users in difficult times. This realisation helps individuals to connect with other people believing in the same religious faith. The belief in a force more significant than the individual, as acknowledged by the participants, offers the understanding that they submit their life challenges to that greater force.

The next theme is counselling as support identified by the interviews for this study.

### **5.4.3c: Counselling**

Another form of support, termed "counselling," was particularly identified by all service users (10), some caregivers (11) and all nurses (6) in this study. Service users and caregivers sought counselling to receive advice and to prepare mentally for challenging tasks. For example, caregivers sought advice when dealing with the difficult behaviour of their ward, which is primarily caused by the symptoms of the illness.

#### **1. Service users**

All the service user participants perceived counselling as a relevant support. For example, some views were opined as:

"Yes. They [nurses] come here regularly, every month. They chat with me on their visits. They advise me when they observe anything that is not right. It can be about how I present to them, medication, my trade and general life. I value their visits and the discussions we have. When they don't come around, I don't get anyone to speak with me about my condition and encourage me about my treatment. If I have any questions to ask, I keep them to myself till I see them. Who do I talk to about my condition. People I share the compound with don't care about me and I can't go to them and tell them anything about my health."

**(Agnes, Service user, Female)**

“The nurses visit me and advise me about my medication. Other times they just visit to chat with me to find out how I am doing and discuss ways of looking after myself. Their visits give me the chance to talk with them and reduce boredom and loneliness.” (**Danso, Service user, Male**)

## **2. Caregivers**

11 out of 21 caregivers identified “Counselling” as one of the elements that define support for managing symptoms of schizophrenia. For example, caregivers sought advice when dealing with the difficult behaviour of their sick individual, which is primarily caused by the symptoms of the illness. They opined as:

“Sometimes, when the illness strikes, I call some of the nurses to talk about the delay in her waking up in the morning. They advise me what to do to help. I think it [the advice] has been of help.” (**Taylor, Caregiver, Male**)

“The male nurse who started working with him advised me about how to speak with the patient [service user] who is my son.” (**Connie, Caregiver, Female**)

## **3. Nurses**

Nurses’ perception of counselling affirms the service user and caregiver participants’ views on this phenomenon. For example, the nurses commented as:

“... we see that the patient has a need, not only about the mental illness, but also about anything that requires counselling...” (**Nyarko, Male, 41-50yrs old**)

“We do our part like counselling, ... have conversations with them and help them to solve their family problems...” (**Abrafi, Nurse, Female**).

The excerpts indicate that mental health clinical staff, including nurses and doctors, advised caregivers to exhibit patience and understanding toward their relatives with mental disorders. The recommendation emphasises the importance of maintaining a friendly and supportive relationship between caregivers and their sick relatives. Participants perceived these actions as intended to alleviate the distress experienced by the recipients of support. Psychological support involves fostering effective relationships and communication to enhance caregiving.

The participants acknowledged that providing advice offered psychological support to the service users and, at times, to the caregivers in resolving minor conflicts between the service users and their families, particularly the caregivers. The advice given facilitated effective communication with both service users and their family members. For the nurses, counselling helped instill confidence and cultivate a positive identity for both the sick individuals and their caregivers, minimising any sense of doubt and shame for the service users and their families. Furthermore, it helped foster social interaction and promote the positive identity that healthcare services sought to encourage between the service users and their environment. These factors are evident through the services provided for both the service users and the caregivers.

The study has revealed that support can be divided into three dimensions: general, physical, and psychological. General support is broad and nonspecific, while physical and psychological support addresses specific needs to enhance wellbeing. Physical support includes tangible items such as medication, food, and financial assistance for service users' upkeep. In contrast, psychological support, which encompasses emotional, spiritual, and counselling assistance, is equally vital for the wellbeing of service users. Both physical and psychological support have helped to alleviate the challenges faced by individuals diagnosed with schizophrenia.

The next theme to investigate was the nature of professional support service users received from the mental health service.

## **5.5: Theme B- Nature of Professional Support for Community Service User**

This section looks at the second objective of this chapter, namely, the professional support that the service users receive. This main theme explored the support available to community mental health service users from healthcare professionals in Ghana. Where responses from participants were similar in the second objective of my analysis, I cited them without explaining in detail since they had been elaborated elsewhere in this chapter. The study uncovered several types of professional support (subthemes) including emotional support, counselling, care review, access to medication and treatment and health promotion.

### **5.5.1: Emotional and counselling support**

The two subthemes, emotional and counselling support are identified in Section 5.4.3a (Emotional Support) and 5.4.3c (Counselling) as elements of Psychological Support in Section

5.4.3 above. Therefore, these two types of support will not be expanded into detail again. All participants shared their views on the professional support received by service users.

### **5.5.2: Care review**

Care review is another type of support noted as an important ingredient in relation to mental health professionals' input into the wellbeing of the service user. This involves service users and their caregivers, and the mental health professional having conversations with a view to determining the mental health needs together. It includes assessment of the needs of the service user to help determine the support that the service user needs in managing the illness. The service users are adults receiving treatment for their mental disorder. Reviewing the care offered to the service user is part of the standard of care. It is important to monitor the treatment initiated for the service user. The care review for this study included monitoring the prescribed treatment for the service user and reviewing their mental state. Although service users lived in their own homes, they attended the health centres where they met with their psychiatrists to review their care. They discussed issues pertaining to their mental state, mood, sleep status and appetite. In addition, the community mental health nurses visited the service users at home to monitor their mental health as part of their roles.

It was interesting to note that all participants commented on the care review provided. Extracts are drawn from each participant group. For example,

#### **1. Service users**

“They [nurses] measure my weight, take my BP [blood pressure], temperature and record all this in my folder. They do all this at the hospital when I go for review. They want to ensure I am physically fit and have energy to do things I want to do in the house. I can wash my clothes, take my medicine, and feed myself. I clean my room and lay my bed...They ask about me about the last time I saw ghosts and dead bodies. They ask if I continue to take my medication, and many questions about my mental health.” **(Ago, Service user, Male)**

“... they [nurses] talk to us about the treatment after they ask about whether I sleep well or not... They ask if my illness is getting better or not. I think speaking with my father about my health is helpful. They explain the importance of

medication and the problems that I will encounter if I don't take my medication.”  
**(Gifty, service user, Female)**

## **2. Caregivers**

Caregivers described the nursing activities to include service contacts. The study found such experiences as:

“... They [nurses] make her feel welcome. They visit her and converse with her. She doesn't get anyone to speak with her as the nurses do when she goes... for review... At the review they ask her about her condition, how she feels, has she been taking her medication? ...she misses some dates and why she didn't come for reviews, etc. ... effects of the drug...any change in her? ... If the medications are not working, we tell them. They ask about the wellbeing of the patient and if the medication needs changing, they do it.” **(Osman, Caregiver, Male)**

“...When they [nurses] visit here and find that she is angry, they ask her if she has eaten. Then they will offer her some money to buy a meal. They don't give her money frequently. By the grace of God, I do care for her. We are alone here. I see to it that she is well fed so that she doesn't get angry. As I have explained, once in a while, if they come to meet her in a different mood then they offer her money to buy something to eat.” **(Lazarus, Caregiver, Male)**

## **3. Nurses**

“We visit them in their houses, we find out how they are coping... When we go on visits we go in pairs or threes. We check their mental state, medication, sleep pattern and any other issues with them” **(Abrafi, Female Nurse)**

“... interact with the patient to assess their mental state and find out how they are doing with treatment.” **(Nyarko, Male Nurse, 41-50yrs old)**

The participants cited some of the topics or health questions are asked by the healthcare professionals during care reviews. Care review includes the assessment of the individual in respect of the symptoms and signs observed by the service user, the caregiver, a doctor/psychiatrist and nurses, especially in the community mental health settings. The

assessment of needs, therefore, remains the joint effort of the service user and/or their caregivers and the clinicians. Psychiatrists play an important role in conducting comprehensive psychiatric assessments to accurately diagnose and effectively treat mental health conditions. The assessment form available in the research enclave contains items such as orientation, memory, mood, insight, perception, cooperation among others, and these items are suggestive of the Calgary-Cambridge model of consultation.

In addition to the psychiatrist's assessments, community mental health nurses made home visits to monitor the mood and mental health of service users and discuss their support needs. This regular contact with healthcare professionals ensured thorough monitoring of mental health and timely interventions to prevent deterioration.

The service users and their caregivers volunteered information about the mental health of the former. They also informed the clinicians about the status of medication concordance with service users. The review ensured that the healthcare professionals gained an up-to-date mental health status of the service user. The review meeting offers the mental healthcare professionals the opportunity to reiterate plans for intervention based on information sharing with service users and their families.

The primary objective of the Community Mental Health team is to identify any hindrances to the functioning of their service users. Working together with the service users, clinicians aim to develop a comprehensive plan to enhance the well-being of the service users. This approach ensures that the service meets the needs of its users and is closely monitored while they are at home. Another core function of mental healthcare professionals is to assess coping skills to support the service users in managing themselves safely.

### **5.5.3: Access to Medication/Treatment**

The study reveals the perspectives of participants on medication. The medication for treating mental conditions such as schizophrenia, psychoses, mania, and severe depression and anxiety is known as antipsychotic. Medication acts on the brain to bring relief to the person. This section looks at the role of mental health professionals in prescribing antipsychotic medication to support the service users.

The study identified the mental health nurses as administering injectable antipsychotic (parenteral medication) prescribed by the psychiatrist. Professional nurses remain indispensable in managing medication. Regarding prescribing and administration of

medication for service users as support from the professionals, all participants offered varied opinions. For example,

### **1. Service users**

“... the nurses come home to inject me... I pay for the drug because it is my health, and I benefit from it. The nurses help me to take the treatment. They know the medication I need, and they bring it along to inject me.” (**Gifty, Service user**)

“...If I don't get the medication I will be disgraced because I will relapse and then comes the shame. I have been well for so long and I don't want anyone to see my bad days again. ... I see the doctor for the prescription, and I take it to the pharmacy to buy the drug. I would like to go hungry and be able to buy the medication.” (**Agnes, Service user, female**)

### **2. Caregivers**

This group perceived professional support in terms of how their loved ones got medication as:

“I have requested the nurses to help me get the medicines... So, before the stock of medicine runs out, I go to the hospital and give the nurses money to buy me more. They bring the medicine to me. ... they arrange for the prescription and buy it for me. ... They also showed me a technique of ensuring he takes the medication by concealing it in food and drinks. That's the only way to ensure medication goes into him.” (**Sylvia, Caregiver, female**)

“... there was an occasion when she was really agitated, ... but the professional way they administered the medication to her calmed her down.” (**Alpha, Caregiver, Male**)

### **3. Nurses**

“...we... visit the home of the patient to see ... they are complying with the treatment regimen... is very important. (**Dosu, Male Nurse, 31-40yrs old**)

“...if you find a patient who is relapsing and the family don't have the money to buy the medication, we buy the medication for them. ...We don't claim back the money we use on the patients from the organisation. ... We are helping our

fellow humans in need. I want to repeat, there is no way we can claim such monies and we do it to help them.” (**Yacoba, Female Nurse, 41-50yrs old**)

“...The newer medications are on the market, but they are expensive, and they [service users] cannot buy them... Sometimes, we buy the medication for some poor patients and supervise them to take it...” (**Nyarko, Male Nurse, 41-50 years old**)

All the participants reiterated the clinical staff members’ role in helping the service user to access and take their treatment except one caregiver who did not find the medication helpful as shown below:

“...One of the male nurses brought her some medicine but he does not come here anymore... The medication never helped her. Their visits and the medication did not offer the expected relief. I did not observe any improvement in her condition at the time.” (**Fabia, Caregiver, female**)

Fabia’s perception aligns with the idea that a short course of antipsychotic should be enough to make her sick relative well. She noted that the supply of free medication to her sick relative had stopped and therefore she had discontinued treatment for her sick relative. It is therefore unsurprising that she believed that the medication never helped her sick relative. Conversely, all participants maintained that the nurses arranged to make prescriptions available for the use of the service users. By this, the community mental health service nurses helped the service users to be concordant with treatment and to remain mentally stable for a considerable time.

The study indicated participants’ positive attitudes towards allopathy and the nurses’ involvement to ensure service users accessed some treatment. The effectiveness of the antipsychotic encourages its use provided the service users and their family caregivers had the resources to acquire it.

The next subtheme is about health promotion which is carried out by the nurses.

#### **5.5.4: Public Health Education/Health Promotion**

The nurses’ perception of health promotion involves sharing of health information with health professionals, service users, caregivers and the public, making suggestions about activities to develop and increase the appropriate knowledge. The mental health service educational programmes offer the opportunity to build knowledge and enhance confidence in improving

the understanding of mental disorders and mental health. Education is meant to improve the mental health of the people and improve the skills to manage mental disorders.

### **1. Service users**

“They [nurses] talk to me about the illness. They help me to understand the ways of reducing relapse of my illness; I get a lot of advice about the illness when I meet them. They also help me to comply with medication. Once the time is due for my depot injection, they come to inject me, and this helped me to stay longer in the community.” **(Gifty, Service User, Female)**

“The only help we get is the way they advise us. They [nurse] talk to us nicely. They give us verbal information to help improve our health... They talk about things that are not good for us. For example, alcohol and other things that are not good for one’s health. I did not know alcohol was bad for my health until I listened to the health talk on alcohol. I have since stopped using alcohol.”  
**(Sara, Service User, Female)**

**2. Caregivers:** Caregivers’ responses around health promotion can be likened to the pieces of health advice they receive from the clinicians to improve the health of their sick relatives. This is discussed under subtheme 5.4.3c (Counselling).

### **3. Nurses**

“We give them health education... about the conditions of their relative and this affects the way families relate to the patients. ... we are doing a lot to raise awareness of the illness and to encourage people to seek help. Also, our organisational talks at the marketplace, workplaces, and schools include ways of dealing with stigma. It is not everyone who comes to the mental hospital to obtain information. ...We do the talks on radio, we go to the shops, organisations, and schools, and anywhere two or three people are gathered to do their own thing.” **(Yacoba, Female Nurse, 41-50yrs old)**

“We do health education... We pick a topic to educate the public... we reach out to about two thousand or more people in the community in one week.”  
**(Dosu, Male Nurse, 31-40yrs old)**

“Mondays are for physical health and psychiatric issues in the Outpatient Department. Tuesdays are for home visits. Wednesdays are for school health

talks in the community. Thursdays are for organisational health talks in the community and include people in the market, drivers, and many we can identify. On Fridays, we go for multidisciplinary meetings, which ends the week's itinerary. Every second Saturday of each month, we attend the pregnancy school organised by the hospital. We go to educate pregnant mothers about pregnancy and related mental health issues, like post-partum psychosis (PPP).” (**Anane, Male Nurse, 41-50yrs old**)

“Support is through...education we have been giving in the catchment area, during organisational visits, home visits and follow-ups.” (**Ayitey, Male Nurse, 31-40yrs old**)

The community mental health nurses are committed to delivering educational programmes for public health across diverse settings in the country. This research exemplifies the nurses' unwavering dedication to their profession and their commitment to providing invaluable health education to those under their care. Through health promotion facilitation, nurses strive to raise awareness about mental health issues in the community.

It is not surprising for another participant to highlight the nature of education the service offers as part of its care towards the service user and the public. The participants identified health education as covering individual service users and the public. The mental health service continues to offer mental health education across the study enclave. The facilitation of education by the nurses is aimed at improving the mental well-being of the people in the community.

The nurses offer education to groups of people such as students at both primary and secondary schools, petty traders at the local markets, and drivers. In addition, nurses within this sector have a responsibility to educate service users about their health, providing them with information about their condition and treatment. The community mental health service is dedicated to promoting the wellbeing of individuals diagnosed with mental disorders by delivering personalised mental health education that caters to the specific needs of each service user. Through this education, service users are empowered to safely self-manage and better comprehend their treatment.

In essence, community mental health nurses offer health promotion to individuals and the public through organisational talks, aiming to raise awareness about maintaining good mental health. They also play a crucial role in increasing awareness of common mental health

conditions, enabling individuals to recognise and take appropriate action to manage these conditions. Providing such educational services is an essential aspect of community mental health nursing, contributing to promoting mental health and well-being at the community level.

This section delves into the professional support provided to the service users. The study uncovered that the professionals maintained therapeutic engagement with the service users by offering emotional and counselling support, reviewing care, assisting in accessing medication, and providing health promotion. It was also revealed that the professionals' interaction with the service users alleviated their distress. Furthermore, ensuring access to medication involves prescribing and administering parenteral medications to promote the service users' health. The study also highlighted the professional nurses' role in health promotion to enhance public understanding of mental health issues.

The following section will delve into nurses' experiences of caregiving.

## **5.6: Theme C- Nurses experience of caregiving**

Nurses are recognised for providing care to individuals who are ill, including administering treatment and supporting interventions prescribed by doctors. They have direct contact with service users and assist with their healthcare needs by providing healthcare interventions. The understanding of nurses' experience of caregiving aligns with the factors identified in Section 5.4 (Meaning of support) and 5.5 (Nature of Professional support for service users) of this chapter. Participants' description of the nurses' experience mirrors that of section 5.5 (Nature of professional support for community service users). Therefore, only the themes cited here, and another theme not identified in Section 5.5 are indicated below. The following were the findings of nurses' experience of caregiving.

### **5.6.1: Counselling Support**

The subtheme Counselling Support is identified in Section 5.4.3c (Counselling) as an element of Psychological Support in Section 5.4.3 above. Also, Section 5.5.1 (Emotional Support) a psychological support which nurses provide to the service users. Counselling Therefore, these types of support will not be expanded in detail again. All participants shared their views on the professional support received by service users.

### **5.6.2: Care review and Access to medication/treatment**

The three subthemes, Care review, Access to medication/treatment and Health Promotion are identified in Section 5.5.2 (Care review), 5.5.3 (Access to medication/treatment) and 5.5.4 (Public Health Education/Health Promotion) as types of Nature of Professional Support for Community Service Users (5.5) above. Therefore, these three types of support will not be expanded into detail again. All participants shared their views on the professional support received by service users.

### **5.6.3: Advocacy Service for service users**

The nurses' involvement in advocacy is an important nursing task. The nurses ensure that service users healthcare needs are attended to by following the latter up at home. The activities of the nurses to ensure the rights of the service users are safeguarded.

The service users and caregivers did not identify advocacy. However, they have acknowledged that the nurses' professional roles are intended to improve the wellbeing of the service user as detailed in Section 5.5 (Nature of professional support for community service user). Therefore, all the nursing activities are to protect service users and promote their wellbeing such as keeping them safe and educating them about their condition. The comments from nurses are recorded as below:

### **3. Nurses**

“Where service users face certain problems... with their workplace or school, ... We get in touch with the authorities at the workplaces and schools to help resolve these problems. ... the authorities ... respond quickly. This helps better than relatives going to the authorities to get the problem solved.” (**Nyarko, Male**)

When we observe any changes in their physical health, we refer them to other services... especially, concerns about nutrition and others, which are part of their physical health needs. ... We booked an appointment for her to see the dietician today... We must support her through her appointment with the dietician. We escort and speak on her behalf at some appointments with the dietician. (**Dosu, Male**)

Advocacy in nursing is not limited to a single activity; rather, it is interwoven into various nursing responsibilities aimed at ensuring the safety and wellbeing of service users and others.

Providing counselling support, conducting care reviews, facilitating access to medication and treatment, and advocating for the needs of individuals are all essential aspects of caregiving that define the roles of community mental health nurses in the research domain.

#### **5.6.4: Challenges Facing the Community Mental Health Service**

This section continues to present findings gathered from the research data. In the context of the findings under the nature of support received by community service users from the mental health service (Section 5.5); the nurses' experiences of caregiving (Section 5.6) in the community mental health setting and the services provided to caregivers and their suitability (Section 5.7). This various challenges in the provision of the community mental health services were identified in the research study enclave and they became the focus of this section. These included problems with accessing free psychotropic medication, staff training, stigmatising attitudes towards mental disorder, and transportation issues encountered by mental health nurses. In the light of these challenges that impact the support given to people diagnosed with schizophrenia and their caregivers living in Ghana, recommendations in terms of policy planning and support implementation will be made in much more detail in subsequent chapters. However, the identified themes are discussed individually below.

##### **5.6.4.1: Supply of Free Psychotropic Medication for Service Users**

The data indicates that lack of accessing free antipsychotic medication presented a challenge in the management of mental disorders in the study enclave. To gauge a general understanding of the challenges within the community mental health services, participants revealed the challenges in respect of the nurses' roles as healthcare practitioners. Among other perceptions, the issue of medication was raised by the participants. It is evidenced that the community mental service users struggle with access to medication. The extract is shown below.

##### **1. Service users**

“There is no free medication which negatively affects the work of the nurses. This is one of the problems that I think the mental health service faces.”  
(**Thomas, Male**)

“Paying the fees for the medication means that the service cannot provide treatment, and I don’t know how they can tell us that they are assessing the treatment they are providing us with.” (**Sara, Female**).

## **2. Caregivers**

“I don’t think that they have difficulties. I don’t know the reason for not giving my sick mother free medication. I can’t talk much about their difficulties...”  
(**Aba, female**)

“We don’t need the government to give us any money. There is no free medication.” (**Emmanuel, Male**)

The nurses can only give the injection if we buy the medication. If we can’t buy the injection, the nurses cannot give the injection. (**Ishaque, Male**)

## **3. Nurses**

“When a patient relapses, we don’t get free medication to help calm them down... Sometimes we buy the medication for them if we have the means.”  
(**Anane, Male**)

“We need free medication for some patients. When you visit some homes, ... some families don’t have the money to purchase the medication.” (**Yacoba, Female**)

“Where patients buy their own medicines, it becomes difficult to review treatment when they have not got the prescribed medication to start or continue treatment. We don’t get free medication to support such patients’ healthcare. We need free medication for the patients to ensure we provide treatment for all of them.” (**Nyarko, Male**)

Participants highlight the importance of medication in the management of serious mental illness. The nurses are not obliged to spend their personal money on community service users. They do not get a refund for their expenses because they do it on humanitarian grounds. Therefore, the expenses incurred by nurses demonstrate their compassion towards the service users. The study reveals that nurses’ support in buying medication for the service user is indicative of families’ difficulty in raising money to obtain the much-needed treatment for the

sick relative. The lack of free medication in the mental health service is the bane of providing mental healthcare that meets the service users' needs.

Community mental health nurses are currently not authorised to carry and administer free psychotropic medication during their visits to the service user's home. This may impact the ability of nurses to provide necessary care to service users who require such medication. The availability of psychotropic medication is to ensure service users continue to receive treatment uninterrupted. Moreover, the nurses can offer relief to service users whom they find to have relapsed and, therefore, would need emergency treatment to relieve them of their distress. The frontline community mental health nurses' view suggests that when a nurse encounters a service user in crisis, they do not have any medication to offer to minimise the acute symptoms of the mental illness. In situations of this kind, the nurse is unable to administer the appropriate psychotropic medications as they do not have access to them. Thus, many of the service users are unable to follow their care plan and are not concordant with medication because their families have not been able to access it for them. Due to the families' financial challenges, nurses sacrifice at their own expense to obtain prescribed medication for the service user without seeking reimbursement from the families or the institution. The mental health service does not have any provision to reimburse such expenses that nurses may have made as explained earlier in this chapter.

Service users from low economic background maintained their treatment and mental wellbeing vicariously through the benevolence of the community mental health nurses. The nurses' support comes in the form of Physical Support (Section 5.4.2) and their psychological support the treatment above. Providing free psychotropic medication and administration of parenteral psychotropics to the service is a form of physical support to enhance their wellbeing. When the service user receives treatment regularly and maintains a stable mental state, it helps reduce the family's anxiety about the service user and this vicariously contributes to improving the psychological health of the caregiver and the family, which is the psychological aspect of support (Section 5.4.3), this study has found. The mental health services' lack of providing free psychotropic medication to individuals utilising community mental services presents a considerable obstacle for the community mental health nurses to assess medication concordance among the service users.

The study participants underscored the significant challenge of limited access to free psychotropic medication in community mental health service. This emphasises the importance of addressing barriers to medication access to improve mental health outcomes for individuals

in the community. Providing affordable or free medication could significantly enhance the support available to those in need.

In attempting to perform their duties and improving nurses' performance, participants identified irregular staff training as the next sub-theme for discussion.

#### **5.6.4.2: Irregular Staff Training**

Training refers to the process of aligning an organisation's workforce's knowledge and skills with the institution's goals. This challenge facing the community mental health service was identified by only the nurse participants of this study. Irregular training can cause decreased competency. The caregiver and service user participants were silent about staff training since they do not know the training needs of the nurses. All the six nurse participants identified irregular and few courses for nurses and therefore recognised the necessity for more frequent training.

### **3. Nurses**

The term "irregular" was deduced from Anane's interview transcript, while other transcripts, including Nyarko and Yacoba, also revealed the absence of consistent training.

“Once in a while a workshop is organised for us. In a year, we get three to four courses to attend. Some of these courses are charged... No one pays for you. We don't get reimbursed.” (**Anane, Male Nurse, 41-50yrs old**)

“We expect staff to be given regular in-service training... Training is not offered to staff to help them work as expected.” (**Nyarko, Male**)

“Our training is not regular. Since I joined this service in 2013, this is the first official training I have attended...” (**Yacoba, Female**)

The infrequent training for mental health nurses in the research field was identified as a problem in the mental health service. The study identified workshops as the medium of facilitating training. Online courses did not appear in the study as an approach to facilitate learning. Therefore, all the training is facilitated in person, that is, face-to-face. Similar evidence was noted in the field notes. Traditional face-to-face training is common among the people and areas where the use of modern technology (that is, electronic media) to facilitate training courses is not cheap and less accessible.

Another challenge is the payment of training fees. A fee is charged and payable by the attendees for the courses before attendance can be assured, and this can discourage attendance. Moreover, where training is not frequently organised, and it is chargeable, it means only those who can pay will be able to attend it. In these cases, a small number of nurses can afford to attend the training when it is organised. Insufficient training for nursing staff in the capital city is indicative of a broader issue. Specifically, it suggests that nurses located outside of the capital city have limited access to training opportunities. This suggests that the development of the nursing staff may be neglected, and this situation poses a threat to monitoring compliance with staff knowledge and skills.

The nurses projected a sense of feeling undervalued which stemmed from the thought of lacking fresh knowledge and skills to perform their roles. Further to this, the nurses think that they cannot compete with their counterparts in other clinical areas, who receive regular training. They tend to think that they are underperforming because they lack the modern ways of performing their tasks.

Irregular training is a common problem in the research enclave and the nurses are concerned about this. Therefore, there is a need for refresher courses to promote ongoing professional development. Regular training is essential for updating knowledge and skills, ensuring that nurses are well-equipped to provide the best care possible. Addressing irregular training could enhance the performance of nurses, improve patient outcomes, and overall effectiveness of mental health services.

Another perception of challenge facing the community mental health service is stigmatising attitudes towards mental disorder, which is the next sub-theme for discussion.

#### **5.6.4.3: Stigmatising Attitude Towards Mental Disorder**

The stigma associated with mental health covers prejudice and exclusion of service users that impedes their prospects of having gratifying lives. Mental health service users and their families are treated less favourably in the community. It is evidenced in this study that mental health service users and their families are faced with stigma.

##### **1. Service users**

“People do not normally understand this condition very well. The nurses offer some social support. When neighbours see a large group of nurses visiting

someone, it raises the suspicion that something is wrong with the person. The less educated neighbours, especially, make unjustifiable conclusions and pinpoint at you making references such as '*that guy*'." (**Thomas, Male**)

"Who takes me seriously when I contribute to a discussion around managing the home. I have been called many names by neighbours because of my illness. I think people around us must understand that we don't choose to be ill. (**Hilda, Female**)

## 2. Caregivers

"The moment one mentions that they are going to the state hospital, the conclusion people draw is that you are mentally ill and then comes the stigma." (**Hazel, Female**)

If someone wants to marry anyone of the girls here in the house, the neighbours will tell them that '*that house, all the people there are mad*'. That is where I struggle with mental illness and stigma. It brings shame to our family... This is where the stigma affects us. (**Osman, Male**)

"The neighbours say things like, 'this woman is mad, nobody should go close to her, she is crazy' and those kinds of things. People don't want to come close to us... it's like emotional torture for us. It is very heart-breaking for a child [19yrs old] to experience this with no family members around." (**Augusta, Female**)

## 3. Nurses

"There are a lot of people suffering from mental illness hiding in their homes because of ... stigma attached to the illness." (**Yacoba, Female**)

"... families don't want to get too close to their sick person, and the ... neighbourhood want to detach themselves from the family... spread false information about the sick person's family..." (**Ayitey, Male**)

"... some patients and caregivers are hostile to staff because they don't want to see the healthcare professionals." (**Abrafi, Female**).

“When mental health patients attend appointments for general health check-up in the clinic, the nurses in that department exclude them and we always have to intervene.” (Nyarko, Male)

Participants noted that people who are associated with mental disorders are stigmatised. Neighbours who are non-family members of the service users use expressions that are suggestive of discrimination and conscious bias towards the service users and families of the people with mental disorders. It is noted in participants' comments that expressions such as '*that guy*' in their local parlance connotes derogation of service users in this context. The situation becomes difficult for the service user when people who are close to them, such as their own family members, together with neighbours, shun their company. They also misinform others about the service user's situation.

Moreover, it is noted that ideas contributed by people diagnosed with mental disorders are deemed less acceptable because of their mental illness. People disapprove the views of the sick simply because of their mental disorders. Stigma is associated with negative attitudes that can limit their confidence to interact well with people around them and can cause feelings of isolation in those who face discrimination and stigmatisation. The negative attitudes towards the sick entrench the self-stigma. Stigma is identified as one of the factors that hinders the promotion of mental health treatment. The person suffering from a mental disorder and their relatives are reluctant to disclose their problems to seek help. Such hesitation to seek mental health treatment is reinforced by self-stigma, which is internalisation of public concepts of mental illness. Such attitudes can lead to self-stigmatisation, which precludes people from seeking help.

Caregivers are also stigmatised and discriminated against because of their association with family members/wards with mental disorders. Comments that are made about caregivers and their families provides a sense of blemish on them because their family members mental illness. The names used by the people around the sick and their relatives lead to labelling which separates the sick and their relatives from people who do not have a person with mental disorder in their family.

Another challenge faced by mental health nurses is the resentment they receive from service users and their families. Some individuals who prefer not to be associated with mental health service do not accept visits from community mental health nurses. The visits may be interpreted by neighbours as someone in the household having a mental disorder, leading families and service users to restrict the nurses from visiting to avoid suspicions.

The study identified institutional discrimination against people with mental illnesses. Nurses in the general health department in the research enclave discriminate against people with mental disorders as noted above in the comments by a nurse. Nurses who have been trained as General Nurses often show reluctance to work with mental health service users. When these nurses know that a patient has a mental disorder, they may hesitate to provide the necessary care. A nurse participant notes that the approach of general health nurses towards community mental health service users is unacceptable, and they intervene when they witness discriminatory practices. However, individuals who do not have a mental health nurse to advocate for them may experience delays in receiving care. It is therefore important to increase understanding of mental disorders and address issues of stigma and discrimination surrounding them.

The pervasive stigma surrounding mental disorders persists, and the associated issues remain unaddressed. Individuals with mental disorders often face unfair treatment in the research enclave, leading to social isolation and reluctance to seek support from others. Living in solitude due to stigma and discrimination can have a detrimental impact on social cohesion. Providing effective mental healthcare services in such an environment is challenging due to low engagement with healthcare and other support services.

The study has identified another significant challenge confronting the mental health service, namely, the transportation of nurses for their community rounds. The transportation-related issues, as highlighted by the participants, have been expounded in the subsequent sub-theme.

#### **5.6.4.4: Transportation problems for mental health nurses**

The community mental health nurses carry out home visits to service users in the community. These dedicated professionals often contend with unpredictable weather conditions during their visits. As many of them do not have their own means of transport, they depend on public transportation for part of their journey and walk the remaining distance. Participants shed light on the transportation challenges that nurses encounter in the course of their work. Two service users and all caregivers and nurses commented on transportation problems for nurses.

##### **1. Service users**

“The transport fare is high.” (Sara, Female)

The staff incur significant transportation expenses to visit me at my residence. Those who make the trip do so once a month, using public transport and often arriving perspiring due to the distance and weather conditions. (**Mensah, Male**)

## **2. Caregivers**

"You know, I asked them some questions a while ago. Do you walk from one place to another when the sun is scorching? I remember offering them some water, saying, 'Look at the way you are sweating.'" (**Alpha, Male**)

Workers face the challenge of securing access to a vehicle that enables convenient mobility without relying on public transportation. (**Theresa, Female**)

## **3. Nurses**

"There is no vehicle for the clinic to help transport us on home visits. We travel around using public transport, and this is a challenge...nurses get travel allowance of GHS 20.00 a month and this is not enough, and it is not paid to staff on time. The transport allowance is nothing to be proud of because before you finish one visit to a patient, half of the monthly allowance is spent. So, we have to use our personal money to do the rest of the visits." (**Ayitey, Male**)

"The issue now is I do home visits when I have money to spare for transportation... no funds for community work like monitoring patients..." (**Anane, Male**)

"The challenges we face are transportation, insufficient funds..." (**Abrafi, Female**)

The community mental health nurses require transport for their rounds in the community. Participants identified different issues with transportation. The nurses' rounds include visits to individual service users and other organisations such as schools and clinics organised in chapels in the community. The mental health service nurses identified home visits as one of the roles they perform. In addition, the nurses visit other organisations' sites and schools to deliver health educational talks and other activities in the community. They resort to using public transport, which they deem as challenging. For example, travelling between the office and service users' homes, and between the office and other places they need to visit to carry out their official tasks, require the use of public transportation. The time wasted waiting for the

minibus to load up before the journey starts to or from a visit would result in delays at appointments or spending longer hours commuting.

The nurses identified insufficient financial support for transportation, which increases strain on their resources. The monthly travel allowance of 20 cedis (£3.64), which is not consistently paid, is inadequate. As a result, the nurses are compelled to personally fund transportation expenses for these visits. Nurses who are unable to fund transportation costs may not visit regularly and this implies delaying care provision to the community service users. Transportation issues, therefore, compromise the continuity of care for service users. It can be distressing for individuals with chronic mental health issues who require regular monitoring and support.

Not having access to an official vehicle poses a significant challenge for nurses, as it hinders their ability to move freely without depending on public transportation. This limitation can impact on their efficiency and responsiveness in providing care, especially in community mental health settings where timely intervention is crucial. Enhancing access to reliable transportation options would improve their ability to effectively serve service users and could lead to better outcomes in mental health support.

In this section, the study has examined the challenges faced by nurse participants in their institution. The mental health service does not provide free psychotropic medication for service users who cannot afford it, impacting the nurses' work in the community. Additionally, challenges include irregular staff training, stigmatising attitudes toward mental disorders and the mental health service, and transportation issues. These challenges significantly affect the nurses' ability to provide responsible care to service users and efficiently serve the community. Addressing these challenges requires systemic changes, such as providing better transport allowances, supplying free psychotropic medications, and improving training opportunities and attitudes toward mental disorders. Implementing these solutions can improve the nurses' working conditions and enhance the quality of care for service users.

### **5.7: Theme D- The Services Provided to Caregivers and Their Suitability**

This section of the thesis delves into the support provided to caregivers by mental health services and their suitability. The study revealed that caregivers benefited from the Community Mental Health Service, particularly through their interactions with the clinical staff members. However, there is some debate regarding the assessment of caregiver needs among the study

participants. The subthemes below (access to medication/treatment, counselling, public health/health education, visitation reduces cost of travel, and assessment of caregiver needs) shed light on participants' views concerning the support offered to caregivers.

### **5.7.1: Access to medication/Treatment, Counselling (Advice), and Public Health/Health Promotion**

The three subthemes, 5.5.3/5.6.2 (Access to medication/Treatment), 5.4.3c/5.5.1/5.6.1 (Counselling, which participants identified as synonymous to Advice), and 5.5.4 (Public Health Education/Health Promotion) are features of the nature of professional support as in Section 5.5 above. Therefore, these three types of support will not be expanded into detail again. Participants shared their views on the mental health service's support for the caregivers through the help the nurses and doctors offer the sick relatives. Acting in the fiduciary role, the nurses help the sick and their caregivers to access prescription, offer health education and advice to improve the mental wellbeing of the sick, and engage in mass education to benefit the caregivers and the sick. These constitute the support the mental health services offer to the caregivers.

In addition to these themes, all participants identified visitation reduces cost of travel for treatment which is explained below.

### **5.7.2: Visitation reduces cost of travel**

#### **1. Service users**

“When the nurses visit us at home, they talk to us about the treatment. They don't talk to me alone. I think speaking with my father about my health is helpful. I don't need to go to hospital first before I get my treatment. I can add my taxi fare to buy my medication. They explain the importance of medication and the problems that I will encounter if I don't take my medication.” **(Gifty, Female)**

“The nurses visit my mother. I don't know what they discuss. I know they come here to speak to her. She knows what she wants. When you see her, you can speak to her.” **(Danso, Male)**

“I do not go to the hospital before I get my treatment. The nurses know when I am due for my injection. So, they buy with their money, and I refund it to them. This has cut down the cost of my travel to the main hospital before I can get my treatment.” **(Mensah, Male)**

## 2. Caregivers

“The nurses’ visits to us have reduced the cost of travel to the hospital.”.

**(Lazarus, Male)**

“For them (nurses) to come here is very helpful. ... The rate ... they’ve been visiting, I think it’s good. Because anytime they come around, they observe the patient’s presentation. Whether he’s doing well or not... Why it is beneficial for them to come and see the patient is because they see things for themselves. **(Theresa, Female)**

“... it is beneficial for them to come and see the patient because they see things for themselves. They offer advice immediately and we can act on their advice without delay. This helps us to keep our mum in good mental wellbeing. This also helps to reduce my travel costs to the hospital for reviews.” **(Aba, Female)**

## 3. Nurses

“I know some of my colleagues give the family a small amount of money, say 10 cedis to buy medicine or to pay transportation to the hospital. As we visit them, they do not come to the hospital that often. The patients who are stable in their condition, they come to the hospital once every three months and they don’t spend on transport fares to the hospital that much.” **(Anane, Male)**

“Also, we support the families through our visit. Our visits help them to cut down on their travel expenses to the hospital for minor issues. We collect information and share with our doctors and where they must see the psychiatrist we invite them for review.” **(Ayitey, Male)**

This section demonstrates the mental health service support offered to the caregivers to continue to manage their sick relatives in the community. The study has identified the support for the caregivers to include *Access to medication/Treatment, Counselling (Advice), and Public Health Education/Health Promotion*.

However, participants were split on the notion of support caregivers received from the community mental health service, when they identified assessment of caregiver needs (5.7.3) as discussed below.

### **5.7.3: Assessment of caregiver needs**

Caring for a service user with a schizophrenic condition is essential. This act has its rewards and challenges and can cause caregiver burnout. This has necessitated assessing the caregiver's needs, to ensure that emerging problems likely to impact their health can be identified and addressed. Investigating the difficulties of the caregivers offers the opportunity to learn about their needs to enable services to support the group better. The essence is to discover what might help make their role as caregivers easier. The general perception of the caregivers in this study is that they have not been assessed for their needs, as the following comment illustrates.

This section looks at the possibility of assessment of the needs of the caregiver to understand any risks associated with the family of the service user. All the caregivers and service users do not believe that caregivers are assessed for their individual needs. In addition, apart from two nurses who admitted assessment of caregiver needs, the rest reported that they did not assess the needs of caregivers. The participants opined as below.

#### **1. Service users**

“The nurses do not ask about how she looks me. All depends on money. If my daughter has money, then the situation will be better. Sometimes I ask for GHS2.00 to buy porridge. She tells me she does not have any money. Without money she cannot help much.” **(Hilda, Female)**

No. I am not aware of any support my caregiver receives. None. The nurses do not speak to my sister who is my caregiver. They visit me and we talk about my health. **(Thomas, Male)**

#### **2. Caregivers**

“When they (nurses) visit, they talk to me about how to look after her. ... They explain things about helping her (my patient) to feel relaxed. They do not ask me if I need any help because I am not their patient.” **(Aba, Female)**

The nurses come over to administer the antipsychotic injections to my brother; that is the extent of the support we receive. Regrettably, the nurses have not engaged with us regarding our needs as caregivers. **(Banta, Male)**

“They [nurses] don’t give me any information during their visitations. No information from the team. The nurses only speak to my sister who is their patient.” (**Osman, Male**)

“I don’t get any help from the service. No one has assessed me to know my needs.” (**Zane, Caregiver**)

### **3. Nurses**

“... Caregiver assessment is done by our service and the form is Depression Anxiety Stress Scale (DASS).” (**Ayitey, Male Nurse, 21-30yrs old**)

“We don’t have any assessment tool for caregivers. We use our discretion. Sometimes, when we go into the house and observe the interactions, we make a decision to assess the caregiver. Sometimes, based on the kind of report we get from the patients, we decide to assess the caregiver.” (**Abrafi, Female Nurse, 31-40yrs old**)

Ayitey and Abrafi’s excerpts reveal that caregivers are assessed clinically. Ayitey reveals a tool called Depression Anxiety Stress Scale (DASS) for assessing caregivers’ mood. However, Abrafi denies the existence of any tool designed for caregiver assessment. The completion of caregiver needs assessment can be isolated cases. The fieldwork noted that there was no caregiver assessment form, and the nurses had no record of caregiver assessment completed in the research enclave. The paucity of assessment records for the caregiver raises inconsistencies about perceived nurses’ assessment of the caregiver. The use of discretion in assessing caregiver needs suggests a lack of structure to ensure a fair system is in place to support the mental health needs of caregivers.

Contrary to Abrafi and Ayitey, the other four nurse participants denied the existence of any caregiver assessment of needs as exemplified in the extracts below.

“We don’t have any special arrangements with the caregivers. We do not have any form to complete for our conversations with the caregivers.” (**Yacoba, Female**)

“Currently, we don’t have or do any assessment of caregivers. No.” (**Nyarko, Male**).

“No. Also, we don’t have any assessment tool for the relatives.” (**Anane, Male**).

“No, we don’t have any actual laid down procedures to assess the caregivers.” (**Dosu, Male Nurse, 31-40yrs old**).

The overwhelming evidence is that the needs of the caregivers have not been assessed. Also, there is no assessment template to guide nurses to complete the needs assessment of the caregivers. The absence of the tool is a reality that the assessment of the needs of caregivers is not something that forms part of the functions of the community mental health services in the enclave. There is no policy that guides caregiver assessment of needs.

The institutional neglect of the caregiver needs suggests institutional discrimination of the caregiver. The mental health service in the research enclave does not have any formal arrangements to assess the needs of the caregiver. The nurses who believe they assess caregivers consider their mundane conversations with the caregiver as an assessment of the caregiver’s need. Such conversations may lack clinical purpose. For any information to be useful to the caregiver, it is imperative for the institution to design a plan to assess the caregiver and the sick family member and design tools and services that best gather information on meeting their needs.

## **Summary of Findings**

In an attempt to explore support given to people diagnosed with schizophrenia and their caregivers living in Ghana, several findings were identified and organised as themes. These were:

- (a) the perceived meaning of support for service users
- (b) the nature of professional support for community mental health service users
- (c) the experiences of nurses providing care in the community mental health setting
- (d) the services provided to caregivers and their suitability, and
- (e) The challenges facing community mental health services.

Following these findings, recommendations for areas requiring policy planning and support implementation will be made. Participants conceptualised the meaning of support for service users in terms general, physical, and psychological. Professional support for service users included emotional, counselling, care review, accessing medication/ treatment. In terms of

nurses' experiences of caregiving, it was similar to the other themes and included counselling support, care review, access to medication/treatment, health promotion and advocacy for service users.

On the part of the services provided to caregivers and their suitability, caregivers had access to medication/treatment for their sick relatives. Caregivers also got counselling (advice), public health education, and receive home visitation from nurses which reduced the burden of having to travel to the health centres for healthcare reviews. Some nurses also provided general health and wellbeing assessment for caregivers. Challenges facing community mental health services were numerous. For instance, the healthcare was poorly resourced, ranging from the availability of medication, training of staff on social issues such as stigmatisation of mental health disorders. Given the challenges, recommendations will put forth to remedy these challenges. In general, these findings cast a useful light on the understanding of the support given to people diagnosed with schizophrenia and their caregivers living in Ghana, in terms of issues, challenges and possible remedies.

## **CHAPTER SIX: DISCUSSION OF FINDINGS**

### **6.1: Introduction**

This chapter discusses the findings of the study. These findings are also presented in the context of the conceptual framework of the EMHP (McLeroy et al., 1988), together with Arnstein (1969) Eight rungs ladder of citizen participation. These discussions are therefore situated in the larger context of the aim of this study, which was to explore the support given to people diagnosed with schizophrenia and their caregivers living in Ghana. This study specifically investigates the support provided to individuals diagnosed with schizophrenia and their caregivers who reside in the La-Nkwantanang-Madina Municipality of Ghana. The study focuses on community care within this specific area of Ghana. This is done by posing the research question shown in section 1.4 Research Aim and Objectives. This is further facilitated by the objectives of the study, which are cited in chapter 1 (see 1.4.2 Research Objectives).

Community mental health services are responsible for supplying preventative, promotive, and therapeutic healthcare outside of hospital settings, while also educating the public about mental health. To upgrade these services, it is imperative to factor in the diverse aspects that impact the experiences of service users and their families. This research scrutinises the support that is available to community mental health service users with schizophrenia and their caregivers, with a specific emphasis on care provision within the community. With mental health care services shifting from inpatient care (WHO, 2022d), family members are increasingly providing care for their kin with schizophrenia. However, from the literature review, there is little knowledge about the type of support that caregivers receive from community mental health services or their acquaintances. It is important to address the well-being of caregivers and their sick loved ones as a societal concern. This involves researching the challenges they face in providing mental healthcare at home and promoting the overall health of both the service user and their family. Prioritising mental health within these populations is essential to improving and maintaining the health of our nation (Thorncroft and Tansella, 2009).

The literature review indicated that many studies have been conducted on social support and positive health adaptation in promoting health needs. Social support in community mental health is not new (Steigen et al., 2022). Despite the plethora of evidence for community mental health services, there is a gap in the literature regarding social support for people diagnosed with schizophrenia and their caregivers in Ghana.

In this chapter, I therefore discuss the crucial findings of the study regarding the participants' views and types, or nature of the services provided to service users and their families as support, the experiences of nurses providing care, the services provided to caregivers and their suitability and recommendations to support the sector. These findings are drawn from chapter five. Furthermore, these discussions are done in connections with the general findings, existing literature, and contributions to knowledge and when applied against the finding or main themes of the study allows for a unique exploration of the support given to people diagnosed with schizophrenia and their caregivers living in Ghana.

The discussion in this chapter is therefore facilitated with the use of the findings which were conceptualised as the following themes:

- (a) the perceived meaning of support for service users
- (b) the nature of professional support for community mental health service users
- (c) the experiences of nurses providing care in the community mental health setting
- (d) the services provided to caregivers and their suitability, and
- (e) recommendations for areas requiring policy planning and support implementation.

## **6.2: Objective 1-To investigate support for people diagnosed with schizophrenia from the perspectives of individuals with the diagnosis, their caregivers, and the professional nurses.**

The first objective of this study is to investigate support for people diagnosed with schizophrenia from the perspectives of individuals with the diagnosis, their caregivers, and professional nurses. To address Objective 1, this was facilitated using the theme (a) the perceived meaning of support for service users which was also conceptualised as a finding.

### **(a) the perceived meaning of support for service users**

The study identifies general, physical and psychological meaning of support as perceived by the participants (service users, caregivers, and nurses) of this study.

Using the EMHP framework, all components of the framework, which are individual, interpersonal/family, organizational, community, and policy, impacted the perceptions of the concept of support for service users as entertained by participants from their unique positions. This is because community mental health service exists to provide services to promote the

mental health of the individual and the larger community. In promoting the importance of mental health to the community, many activities involving groups are considered, hence social support. The support transacted within the social context is therefore expressed as the phenomenon of interest for this study.

The study evidences that social support culminates in human connections. Without the presence of human interactions to bring the support to bear, social support fails to exist. For instance, though from the EMHP framework, the individual and family may perceive support in different ways, this perception of support is however, impacted by organisational, community, and policy aspects of the framework. For example, organisational, community and policy issues affect the type of support service users get or do not get. This is in the context that mental health services are poorly funded in Ghana (Ae-Ngibise et al., 2024). In addition to this, the service users can in theory occupy all the eight levels of the ladder of citizen participation (Arnstein, 1969). However, in practice, and during this study, service users were usually noted to be occupying the two lower levels of the ladder (Manipulation and Therapy). This was because they usually defined or perceived support in the context of what mental health practitioners did for them (that is the 'support' – services they provided). This included counselling and administration of treatment, such as giving psychotropic medication. Throughout the study, it has been established that the service users' welfare and functioning in the community require the contribution of others. Prior to onset of, and during the acute phase of the illness, and after diagnosis of the condition, the service user continues to live with their families in the community and receive support from families. To aid better understanding of the impact of the EMHP framework and ladder of citizen participation and the way participants perceived support, the support tree can be used (see Figure 6.1).

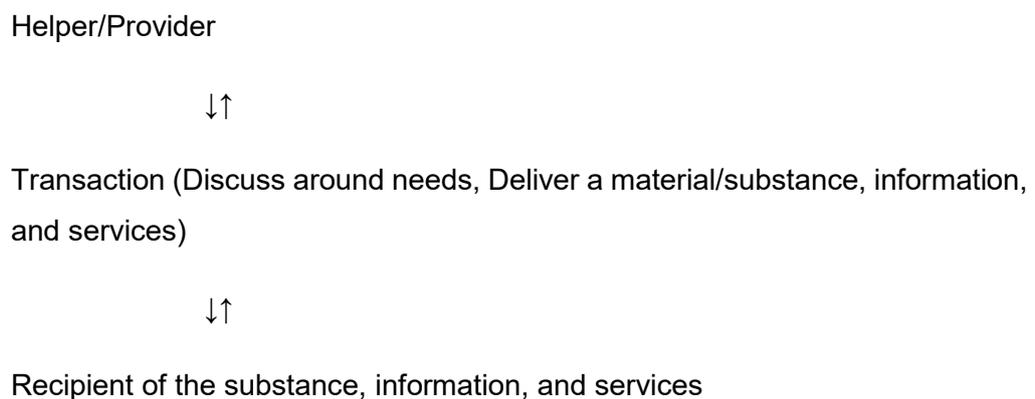


Figure 6. 1 Showing the support tree

Figure 6.1 portrays the summary of the support tree. Achieving relief for individuals requires various components, and one of the most critical is support. However, how this support is

given or received and originates from can be identified from across all the parts of the EMHP framework, and the role of service users in this support provision. The role can rest on any of the rungs of the ladder of citizen participation. Thus, from the Individual domain on EMHP framework and ladder of citizen participation, it is relevant to actively participate in the process of providing support required. However, such support can take on either a proactive or reactive approach and can be influenced from the organisational/institutional and community domains of EMHP framework. Proactive support could involve health professionals identifying and addressing difficulties to alleviate the challenges faced by individuals, meeting their needs, and minimising problems in managing schizophrenia. Furthermore, support plays a vital role in monitoring care services. It is crucial to be proactive in managing schizophrenia, and timely support is necessary for prompt attention. It is synonymous to prevention is better than cure. Therefore, the interplay between the various parts of the EMHP framework (which participant also occupy) and, where service users rest on ladder of citizen participation, shape the way participants see support or what it means to them.

Service users therefore receive physical and psychological support from their families. Families in physical terms provide, shelter, fund service users treatment, food, while in terms of psychological support, families provide emotional and spiritual support. The evidence indicates that these two human factors (physical and psychological support) in promoting health cannot be ignored (Schult et al., 2022; Ashida & Heaney, 2008). This is because the role of caregiving is often assumed by family members, it comes with its own set of challenges, requiring additional effort to address the difficulties arising from the illness (Sun et al., 2019).

The decision to create a meaningful experience rests with the service users, caregiver and the nurses it is a choice that requires a level of intentionality and effort, but the impact of this decision can be profound. By making a conscious effort to create a purposeful experience, participants can derive a greater sense of fulfilment and satisfaction from the care they receive as service users or work the caregivers and nurses perform while giving care. This can lead to improved outcomes for those receiving care, as the caregiver is more likely to be engaged, attentive, and empathetic. Ultimately, the decision to make caregiving meaningful is a personal one, but it is a decision that can have a significant impact on both the caregiver and the care recipient. However, as noted earlier, this is mediated by factors in the EMHP framework and ladder of citizen participation and can share the perception of the meaning of support for service users, from participants' different perspectives.

This section of the study reveals the discussion about the support that service users receive in the study enclave. It will be considered from two perspectives, from the family including the

caregiver (informal) context and professional (nurses) approach to caregiving. These perspectives hinge on relationships that range from individual, interpersonal/family, to policy in the EMHP framework with service users occupying all or different levels of ladder of citizen participation at various points during their ill mental health. Thus, these aspects of EMHP and ladder of citizen participation cut across or intersect with the relationships between the service user, their families, caregiver, and mental health professionals.

The perception of the concept of support by participants was seen in general, physical and psychological terms. In general terms, participants had a varied understanding of what support meant to them, and mostly these covered physical and psychological aspects. As such physical and psychological terms of support are the ones discussed in detail here in this context.

### **6.2.1: Physical Support**

The results suggest that Physical support is a valuable form of assistance that involves offering practical and tangible aid to others (Scott, 2023). This may include taking on responsibilities like household chores or running errands for them, allowing them to focus on resolving any issues they may be facing. Additionally, physical support can involve actively helping someone manage a problem as part of social support. For example, a caregiver or friend providing physical support to someone going through a tough time may offer to accompany them to appointments, assist with transportation, or even offer temporary lodging. Ultimately, the aim of physical support is to provide individuals with the practical assistance they require to overcome obstacles and enhance their overall sense of wellbeing. The current study contributes evidence to Scott's (2023) explanation of physical support. The results of this study suggest that the service users experience physical support offered by their families. The service users and their caregivers have already endured chronic disease burden. Once treatment commences, it is imperative to prioritise the quality of life of patients with schizophrenia, going beyond mere clinical symptom improvement. (Valiente et al, 2019).

The emphasis on material support illustrates the tangible items such as money and consumables, which constitute the basic need for the sick. Without meeting the basic need, the service user cannot physically survive their illness. Therefore, finance becomes the factor for providing food, clothes, accommodation, other materials, paying for healthcare services delivered, and practical help offered such as caring for the sick in the community. This study suggests that physical wealth such as cash is important in providing support for the service user.

Financial burden associated with management of mental disorder among the community service users is noted in this study. The availability of finance and other tangible assets plays a critical role in enabling service users to attain financial independence and effectively manage their cost-of-living expenses.

The financial wealth for the service user will enable them to make out-of-pocket expenses for their medication and other perceived needs. The financial capacity of the service user improves their mental health and general wellbeing. A service user diagnosed with schizophrenia with access to cash wealth may be dependent on the support gained from their family and/or take up a form of paid employment. The retention of employment by service users confers certain benefits on them as argued by Haro et al (2011). The merits include earnings from the job, stable mental state, and improved health. Moreover, both unpaid and paid jobs are perceived as essential part of the life of a person diagnosed with schizophrenia (Durgoji et al., 2019). In the lives of the service users in the study, having paid work is important to those who are well enough to perform activities that can give them some money to pay for their treatment and general upkeep without having to depend heavily on their families for all their needs to be paid for. Paid work offers the service user a sense of control of their own lives and enhances their quality of life, and potentially extend positive caregiving because the elements of treatment and care can be met with little difficulty where there is enough money for the service to secure those items.

However, competitive work could have a negative impact in that service users could be deemed competent to meet the challenging demands of the job, especially, where pay is an indicator of demanding roles (Bell et al., 1996). Service users would therefore need support to secure and maintain paid employment. In this regard, service users who can work for pay need supported employment. In Ghana, about 1.34 million people are employed (International Labour Organisation, ILO, 2022). Unemployment is rated as a major problem facing the country (Institute of Economic Affairs, 2016). It is therefore challenging for service users who are not already employed to secure employment in such an economy. Even the self-employed could not volunteer information on their earnings, and this indicates that they are faced with financial challenges. This makes unemployment a common phenomenon in the study enclave.

The difficulty faced by service users is the discrimination associated with the mental disorder with which they are diagnosed. Society's poor perception of mental disorders presents a challenge for the service user because employers' knowledge of a service user's conditions provides the basis for employers to put the service user applicants or those already employed

at a disadvantage. Service users indicated that employers were concerned about risks such as risk of violence towards others, difficulty coping with the role among others.

The current study confirms previous studies by Marwaha and Johnson (2005), which indicated that disclosure of mental illness threatens service users job prospects, and by Quinn, et al (2004), which found that the acceptability of the service user as a person remains wanting in the current times. One potential reason for employers' reluctance to hire individuals with schizophrenia is their fear of increased sick leave. This concern may stem from the fact that schizophrenia can lead to periods of disability and require time off for treatment. As a result, employers may view these individuals as less productive or reliable, leading them to avoid hiring them altogether. These discriminatory practices against the service users can be demotivating for them to seek employment in the public sector. However, same demotivating factors can become the motivation for some service users with knowledge and skills to work for themselves to do so. Section 3(e) of the Mental Health Act 846 (2012) mandates the prohibition of discrimination and stigmatisation against individuals diagnosed with mental disorders. However, there is a need for enhanced monitoring to facilitate better implementation of this section, thereby improving the quality of life of service users in Ghana.

In the study, service users confirmed that they worked for themselves as petty traders and artisans (Kente weaver/ traditional cloth weaver, hairdressers, and draftsman among others). These are service users who had learnt a trade and identified themselves by the trade. Working for themselves provides them the opportunity to plan their lifestyle. Self-employment is suitable because the service user can work at their own pace to generate income for their upkeep. This study confirms a previous study that found that service users are unfit to work regularly as a result of the symptoms of the illness and the effects of psychotropic medication (Doku et al., 2008).

Having a job is essential for one's well-being, as it fosters confidence and self-worth (Aylward et al., 2018). However, being without work and any means of income can be a daunting challenge, especially for those who depend on it to cover their expenses, including medical treatment and daily upkeep. Unemployment is linked to both physical and mental health issues, which compounds the difficulties faced by those already grappling with financial hardship and mental disorders (Waddell and Burton, 2006; Stevens, 2023). Being jobless, financially strained, and mentally unwell is a reality (Bell & Blanchflower, 2010). Wilson and Finch (2021) argue that unemployment can lead to a cascade of physiological effects, owing to the excessive stress that it can induce. This can, in turn, have a negative impact on an individual's mental health and well-being, manifesting in the form of depression, anxiety and

a lowered sense of self-worth. Therefore, it is crucial for individuals in this category (service users and caregiver participants) to seek employment as a means of pursuing financial stability, which is their primary motivation.

It is imperative to assist unemployed service users in filling their day with meaningful activities. One effective approach is to support them in obtaining employment that generates income. However, where the person lacks the relevant skills, the individual may require vocational rehabilitation to develop employable skills before getting employed (Aylward et al, 2018; Scheef et al, 2017; Unite the Union, 2009). I observed during the fieldwork that most of the service users I encountered had no jobs. These service users depended on their caregivers for their upkeep. Addressing the socioeconomic factors that impact their lives is crucial to enhancing their health and wellbeing (Chen and Paterson, 2006), because the income inequality plays a significant role in the rise of health disparities (Elgar et al., 2015; Viner et al., 2012). The link between income inequality and negative health and social outcomes is well-established (Kondo et al., 2009; Wilkinson and Pickett, 2010). The service user and caregiver participants' willingness to declare their job status accentuate the prevailing low level economic status of the group, albeit undisclosed income. It is imperative to facilitate their access to gainful employment.

Work in general has other values to the employee. Being extrinsic or intrinsic, the significance of work in a person's life and their adherence to established standards are encompassed by work values. It is important to recognise that people have diverse preferences when it comes to their jobs. While some prioritise the economic benefits of a job, others seek personal fulfilment. The former is commonly referred to as extrinsic work values, which encompass elements such as income, working hours, pension plans, and insurance (Gesthuizen et al, 2019). It is further explained that extrinsic values serve the purpose of improving the work environment by creating favourable conditions. This means that a task, even if it may not be inherently appealing, can still be considered acceptable if it offers good compensation or other benefits. In the current study, economic value and other external factors related to work are crucial for the service user participants. Although extrinsic values are important, workers must prioritise their work values and embrace a mindset that is in line with their objectives.

Intrinsic work values focus on the specific content of an employee's work and not just the general circumstances surrounding it. Therefore, enhancing the competences of the employees becomes important to them. These values are crucial for personal development, growth, and realising one's full potential. They motivate individuals from within, empowering them to take action and achieve their goals (Busque-Carrier et al., 2022). People require

competence to ensure their actions have an impact and that they can effectively interact with their surroundings. Moreover, workers crave social connections and care from significant people in their surroundings.

The service user can maintain connection with their social environment through work. Social connection is imperative in the work environment, especially, where work brings the workers together to accomplish the organisation's objectives. Job security is paramount to ensure the continuity of service provision. Work therefore offers psychological wellbeing as, to an extent, it provides security for the service user.

The combined efforts of institutions such as Ministry of Health, Ministry of Social Welfare, and Ministry of Employment and Labour are necessary to build centres across the country for the service users when they feel well enough to learn trades of their choice that can benefit them. Moreover, such training centres can be opened to other members in the community, and this would offer the opportunity for the service users to easily mingle with their peers who do not have diagnosis of mental disorders. Accessing the training centres, be it 'work rehabilitation centre' or 'resource centre' could offer the opportunity to minimise stigmatising attitudes towards the service users with mental disorder. In addition, offering employable skills would offer the confidence for service users whose symptoms are in remission to find some income generating work to do.

### **6.2.3: Psychological support**

The subject of this section of the study is the utilisation of psychological support to identify and enhance the emotional and behavioural wellbeing of individuals. Psychological support can alleviate mental distress alongside mental health medications. While not being expert psychotherapists, mental health nurses offer guidance and knowledge to boost wellbeing, prevent and lessen distress, handle family crises, and improve an individual's capability to operate more effectively.

The psychological aspect of the caregiving is based on a two-factor model propounded by Lawton et al., (1991). According to the two-factor model, caregivers can experience both emotional distress and psychological satisfaction and growth. These two states are not mutually exclusive and are interconnected. The model emphasises that providing care can result in both a burden and relief. These effects represent the psychological impact that caring for someone can have on a person. Caregivers of people with schizophrenia often have a

wide range of emotional responses to caregiving events. It is important to remember that emotions are a natural and inevitable part of the human experience.

Another difficulty is unresolved family dynamics from the past, possibly, when the service user became psychotic and presented as challenging to the family. Moreover, the challenging behaviour associated with schizophrenia is enough to cause stress to the family and the caregiver. These difficulties associated with the prodromal and trajectory of schizophrenia that caregivers encounter can restrain relationships and support networks. Caregivers in this study highlighted emotional burden (Psychological Aspect of caregiving). This corroborates emotional burden identified with the caregiving in the work of Awad and Voruganti (2008).

### **6.2.3.1: Emotional, spiritual, and counselling support**

The current study suggests that psychological support is relevant. Psychological support from this study suggests that emotional support is at the core of this type of support. Emotional support underpins spiritual and counselling support and is of prime importance. This is because emotional support impacts spiritual and counselling support. Thus, spiritual and counselling support are discussed in their broader terms as emotional support. These support structures, emotional, spiritual and counselling support are offered by the caregivers, family members and the healthcare nurses to the service users.

**6.2.3.1a: Emotion** is a psychological state referring to feelings. In mental health care, emotion is expressed by humans and emotions are inherently social. These emotions are considered as senses that are individually appropriate to the prevailing social events (Lively and Weed, 2018; Hochschild, 1983). According to Hochschild's theory (Hochschild, 1983), the act of expressing emotions can be seen as a signal indicating that an individual requires something. In other words, emotional expressions provide valuable information about an individual's needs and desires.

Emotional pressure is known to be linked to caregiving. In defining caregiver burden, Dillehay and Sandys (1990) identify emotional stress as a characteristic of caregiving. The caregiver's default role includes emotional care to the service user diagnosed with schizophrenia (Alexander et al., 2016). In other literature, it is evidenced that caregivers continue to provide emotional support for their sick relatives to help them cope with their difficulties (McFarlane et al., 2003). Caregiving for a person with schizophrenia include the obligation to provide extensive long-term care and the emotional strain associated with providing that type of care.

Providing such care for a service user with a chronic serious mental disorder becomes a cause for emotional burden. However, in the study area, caregivers identify nurses' visits as support for them.

The caregivers require emotional support to maintain their motivation for giving care to their family members with schizophrenia. The support includes providing reassurance and understanding for the caregiver, and to ensure that the support is based on the needs of the caregiver seeking support. Seeking support can feel lonely and sometimes overwhelming and frightening. The loneliness may partly be due to the stigma linked to schizophrenia, especially, with mental disorder. Reassurance for caregivers is relevant to provide the motivation that they can seek support themselves and to make them aware that it is not uncommon for them to encounter the difficulty they face in providing care to a service user diagnosed with the mental disorder. It is more reassuring when caregivers are aware of the services and the individuals who avail themselves to assist in managing the caregiver's personal difficulties. Therefore, for the individual caregiver, it is more relevant to identify their individual needs to offer person-centred support to make it relevant for the individual caregiver. During the data collection period for the study, there was no recognised organisation available to provide relief services to the caregivers. The situation suggests institutional discrimination against the caregivers in Ghana.

Giving care to the person identified with schizophrenia is associated with varied emotions. On one side, the caregiver is faced with the feeling of loss, anger, sorrow, frustration and guilt which are the indices of burden. These are the negative emotions the caregiver feels as they continue to give care to their relative with schizophrenia, especially, where the mental disorder has caused nervousness, grief and worry among the immediate family members. In the event of a family member becoming psychotic and being diagnosed with schizophrenia, the illness also can cause numerous changes in the person, and this will impact on the family. Such impact would include a family member becoming the identified caregiver and having their roles changed from a full-time employee to a fulltime caregiver and would depend on other family members for financial and material support to enable them to support their sick.

Service users find comfort in their relational connections with the healthcare professionals. Effective communication between caregivers and service users is beneficial to manage emotions. The service user and caregiver participants in the study cannot survive the pressures on their own. Negative emotions expressed by the caregivers and service users suggest a need to be listened to so as to manage their needs. They need to be with others to feel less threatened, especially, in times of distress. Individuals need to connect with others for an actual sense of social cohesion. As a social being operating in a social milieu, the

emotion expressed or lack of it, depending on the situation, may create a burden for the sick and the caregiver and the healthcare professionals must be resolved to improve the psychosocial health of the community service user.

This research highlights the importance of emotional support in promoting wellbeing for individuals with chronic schizophrenia. Emotional support involves interactions that foster healthy emotional connections and functionality, particularly among family members and between service users, caregivers, and healthcare professionals. The challenges associated with this mental disorder can be overwhelming for both the service user and their family members. Therefore, it is crucial to provide emotional support to help them manage the distress associated with the condition. By understanding one's emotions and using them to promote functionality, individuals can develop functional skills and maintain healthy lifestyles despite the disorder's challenges. Emotional support can be attained through engaging with others to assist individuals in distress in maintaining a sense of tranquillity. It is crucial for families to maintain prosocial behaviour to consistently provide support to those in need. Those around the service user and their families must apply their acquired knowledge to direct their thoughts and actions (Mayer et al., 2008).

As stated above, emotional support from this study suggests that emotional support is of prime importance. This support is offered by the family members to the service user. The service user needs social network, informal network such as the family and friends or other voluntary groups to act as buffer. As community service users living in their own homes, their environment outside the walls of the hospital must buffer the stress and strains of life. The primary group includes families and friends who constitute the protective factor for the sick. The importance of the primary group is contingent on the quality of the interaction between the service user and the family. The literature conjectures that emotional health and wellbeing factors of social support are crucial to health maintenance and to enhance functioning (Steigen et al., 2022).

The emotional needs of the community mental health service users are relevant in the management of mental disorders. The current study suggests the involvement of service users in family discussions as a very important factor in their quest to feel emotionally secure within their social network, especially outside the hospital environment. The study findings reveal that many service users gain their psychological support from their informal caregivers such as their fathers, mothers, aunties, uncles, siblings, sons, and daughters. Experience of negative emotions for extended period can result in poor mental health and other difficulties. This study supports the previous evidence that negative emotions are associated with distastes and illness (Compas and Lueken, 2002; Gonzales et al., 2016). The illnesses

suggested include physical, mental, and social health problems. It is therefore relevant to argue that emotional health and wellbeing are key to maintaining stable health.

The ability to maintain stable health is closely linked to the practice of active listening (Ricks & Brannon, 2023; Procter-Legg, 2021). By fostering open communication and emotional support through listening, individuals can benefit from the guidance of their social network. As Gardener et al (2011) points out, learning is a lifelong process, and acquiring new skills is essential to thriving in one's environment. It is important to recognise that no one is born with all the knowledge they need, and that ongoing learning is key to personal growth and success. Gardner's Theory of Multiple Intelligences classifies intelligence into two distinct categories: intrapersonal (self-smart) and interpersonal (people-smart). Intrapersonal intelligence is all about self-awareness, encompassing one's emotions, aspirations, motivations, and intentions. Gardiner's theory suggests that developing emotional intelligence is critical to comprehending our feelings and behaviour and identifying our personal needs. In the context of this study, the individuals are accountable for the aptitude of interpersonal intelligence, which primarily emphasises the cultivation and establishment of robust interpersonal relationships with others. Both these intelligences play a crucial role in shaping our social and personal lives. It involves communication and building communities to support individuals in need. Our interactions with others can significantly impact their wellbeing. Hence, by exhibiting positive attitudes towards others, we can encourage them to communicate their needs. Effective communication is critical for creating social bonds and fostering a secure environment where individuals can freely express their needs.

It is essential for the parties involved in the social interaction to learn the ways of maintaining effective communication to address issues around emotions relating to the management of the service user and their difficulties and the family caregiver's burden. Caregiving for a service user may impede family caregivers' competence to take part in other regular activities and impose emotional burden and can impact caregiving (Milton et al., 2022). The caregiver may require frequent reminders to learn and be helped in developing strategies to manage their emotions and that of their wards (service users). Understanding and application of relevant emotions to guide actions, the person gains competences that improve their emotional wellbeing and their mental health.

In this study, emotional support plays a significant role in the effective management of schizophrenia. The nurses have identified emotional support as a vital component that contributes positively to overall health. To facilitate this support, healthcare professionals can offer psychological therapies to service users and their caregivers, enabling them to cultivate

emotional intelligence for better mutual coexistence. By enhancing their emotional intelligence, they can improve their capacity to provide much-needed emotional support to one another. Kring and Caponigro (2010) draw attention to emotional impairments associated with service users living with schizophrenia. It is therefore imperative for the nurses to be aware of this as a negative symptom of schizophrenia and ensure that it is highlighted in their assessment of the service user for attention. Acknowledging the importance of emotional expression, both for oneself and others, is crucial in fostering healthy social connections. To this end, psychological therapies can be tailored to focus on developing skills in emotional awareness, attentiveness to others, and effective management of emotions that may interfere with interpersonal relationships. The mental health service recognises caregivers as partners in providing care for the service user. However, the mental health organisation lacks policies that provide opportunities for caregivers. This study confirms the existing evidence by Corrigan et al, 2014; Corrigan, 2004) that highlight non-existence of policies that offer opportunities for caregivers.

The findings from this study found that the population of caregivers in community mental healthcare remain burdened. They are saddled with social and physical health issues. In spite of the burdens associated with caregiving, this study has identified some alleviation to the burden. Subsequently, it is relevant to consider methods for relieving the burden of caregiving. The approaches identified by this study include physical support, spiritual support, and counselling.

**6.2.3.1b: Spiritual Support** has been indicated to provide emotional support for the caregivers and their family. The study identified practical support family members and friends gave to the caregivers in difficult times. A reflection of caregiving has an adverse impact on participants, with caregivers in particular seeking spiritual support to manage the burden of care. For example, as the frequency of problematic behaviours exhibited by service users increases, caregivers neglect their own healthcare needs and report lower levels of self-rated health (Son et al., 2007). This phenomenon can be attributed to caregivers prioritising the service user needs over theirs, leading to a deterioration of their own health and wellbeing. Consequently, caregivers who hold religious beliefs and belong to a religious group frequently turn to spiritual resources as a means of coping with the challenges of caregiving. For example, in this study, a caregiver was supported by church members to ensure that the caregiver could get a break to sleep. This study supports Nowlan et al (2015) who find

practising religious tenets as a way of coping with stresses of life among caregivers. Adherence to one's religious practices such as prayer, fellowship with members of the same faith, and visitation can instill hope, positivity and psychological well-being in the caregivers. Caregivers seek solace in spiritual exercises, especially when they feel their challenges are overwhelming. This is the moments that the caregivers fall on their religious community for support and to remain resilient in managing themselves. Appealing to the Supernatural is the acknowledgement that the caregiver cannot handle the situation and would like to leave it in the hands of God, as expressed in the parlance of the local people. Moreover, the spiritual belief encourages the caregiver to be more protective in their caregiving role. This study reinforces the evidence of Damianakis et al. (2018), which notes that caregivers adopt spiritual beliefs in managing their stresses.

There is an acknowledgment that acknowledgement that the impact of cultural beliefs and practices have on mental health treatment is crucial in Ghana, Africa and the low-income countries. The current study's findings emphasise the importance of spiritual support in promoting health. In Ghana, seeking assistance from traditional healers and integrating spiritual or religious interventions with medical treatment are common practices. For example, in Spiritual Support, the study participants reveal the role spirituality plays in promoting health. The spiritual dimension of managing schizophrenia in the current study has been acknowledged in other studies such as Asamoah et al, (2014) and Badu et al., (2019) who found religious practices offer social support to the service user and families and to aid healing. Practising religious tenets is a form of therapy for the service user and family who are adherents of the faith because it instils hope in them. Faith-based service providers are noted as the first point of call for healthcare before visiting the health facilities (Nartey et al., 2019). A considerable number of mental health service users do not initially opt to seek care directly at formal psychiatric facilities (Ibrahim, Hor et al., 2016). As a result, mental health professionals must possess a deep comprehension of these cultural factors and show respect for them in their care (Agyapong et al., 2015).

Participants were therefore aware that spiritual support for caregiving activities had a significant impact on wellbeing.

**6.2.3.1c: Counselling** in this study was perceived as advice (support) given by nurses to service users and their caregivers. Therefore, counselling would be discussed under the nature of professional support for community mental health service users (see Theme B).

### **6.3 Objective 2- To examine the nature of support that community service users get from the community mental health service.**

**To address Objective 2, this was facilitated using the finding or theme (b) the nature of professional support for community mental health service users.**

#### **Theme B- the nature of professional support for community mental health service users**

This main theme explored the support available to service users in the community from community mental health service professionals in Ghana. The study uncovered several types of professional support. These included emotional support, counselling, care review, access to medication and treatment, and health promotion. Thus, this section ascertains the specific types of support provided by the community mental health services to service users. Nurses recognise the service's efficacy in treating schizophrenia, underscoring its immense value for mental health care. The support provided by the community mental health service identified in the study includes care review for the service users. However, because participants generally saw emotional and counselling support as similar, and also the nature of the support nurses provided for service users, these will not be repeated.

The nature of support nurses provided, is largely derived from the individual, interpersonal, organisational/institutional and community domains of the EMHP. These domains provide the organisational/institutional structure, inputs and outputs that feeds into the community in the form of the professional support that is provided. It should be added that service users, caregivers and the public can therefore engage with nurses from any point of the eight levels of the ladder of participation.

#### **6.3.1: Care Review for Service Users**

The following aspects will be discussed: a) Assessing service user needs; b) Health promotion for service users, and c) Access to medication and treatment, and d) Counselling.

##### **6.3.1a: Service users are involved in their assessment of needs.**

This is because, to enhance one's health, health systems must cater to the specific needs of individuals. Nurses are also involved in the assessment and monitoring of mental health needs; however, Act 846 (2012) Section 97 prohibits restriction of service user choice. The nurses are therefore authorised by the law to support service users to make choices about their care and this concurs with Meier (2017) stance on the protection of service user rights.

The assessment of needs helps to determine the relevant support to offer the person. It is not needless to find out the individual's 'needs' when it comes to their health and medical treatment. For humans to function and grow, meeting their needs is vital (Beran 2015). A need arises when something is lacking, which throws humanity into a state of 'disequilibrium' (Doyal & Gough, 1991). During times of uncertainty and instability, it is of utmost importance to assist those requiring it. The fulfilment of needs is paramount to maintaining stability, as meeting these needs is vital for achieving a particular state of being, such as the restoration of good health for individuals diagnosed with mental disorders, their loved ones, and clinical professionals such as nurses and doctors. It is essential to fulfil these needs to guarantee the wellbeing of the person and to prevent any possible harm. Consistent with the literature (Ajibade, 2021), support should be offered to meet the needs of a person and the support must be relevant. When something is lacking in one's life, it can create psychological imbalance in the individual in need.

The service users require support to minimise the difficulties they face and be safe, which reflects their human rights. Meier (2017) therefore makes a clarion call for the protection of human rights in health to include active participation of service users in needs assessment and making choices about their health. Active involvement of service users in the study is in alignment with Meier's (2017) call for healthcare systems to empower individuals in making decisions about their care. It is imperative to actively involve service users in the review of their healthcare needs, thereby enabling their awareness of their right to healthcare. Thus, in applying Arnstein (1969) ladder of citizen participation, the desired aim is to enable the service user to operate at the citizen control rung, which is the highest level and ensures active and full engagement and control by the service user of the support that mental health nurses provide. This study also supports Ajibade's (2021) suggestion to nurses to have a holistic view about the service users.

Schizophrenia can cause disability in the service users (Harvey and Strassnig, 2019). The illness can significantly impair the individuals' functional capacity and social competence, leading to unfavourable outcomes. Therefore, the healthcare team must conduct needs assessments to ensure that the service users have the relevant possible care and treatment plans. Access to healthcare is a necessity for the service users to maintain their general wellbeing. This study, uncovers various dimensions of health, including physical, psychological, social wellbeing and mental health care. These comparable areas of need identified in this study is consistent with the findings of Uygur and Danaci (2019), Beran (2015), & Haas, et al., (2012).

Assessing the needs of service users presents an opportunity to comprehend and address various factors that can enhance the quality of life for individuals living with schizophrenia. This research specifically examines the accessibility of psychotropic medications for service users. Monitoring each service user's treatment plan on an individual basis is essential. To develop an effective intervention programme, it is vital to establish, implement, monitor, and review a tailored intervention plan that addresses the treatment concordance needs of individuals. By promoting concordance, clinicians foster a therapeutic environment that empowers service users to express their opinions about treatment decisions and actively participate in the treatment process.

The therapeutic milieu is an alliance between the clinicians, such as the psychiatrists and nurses. It is necessary that the clinicians are transparent in their engagement with service users in the information gathering process to build trust and enhance informed decisions about treatment options. It helps to promote safety and inclusivity, protect service user privacy, communicate about scheduling, navigate financial barriers to care, and ensure continuity of care (Bridges et al., 2021). It is important to be attentive to the service user's choices to demonstrate that their values are respected (Tringale et al., 2022; Elwyn et al., 2012/2017; Haynes et al., 2002). The preferences of the service users considered in the discussion of the treatment plan helps them make informed choices that contribute to treatment plan compliance.

People with severe chronic mental disorders in the community continue to receive care from their families and the mental health services to manage schizophrenia. Care is, therefore, understood as being responsible for someone and executing activities for others to improve health, including mental health treatment (Cornwell & Waite, 2009). Whereas the family caregiver is responsible for offering practical help to the community service user in managing themselves at home, the Community Mental Health professionals are focused on the treatment of the mental disorder and reviewing treatment as part of the care provided. Health care review centralises on topics directly relevant to the practice of management and administration of health care organisations that provide direct health services. In an attempt to review the care of the individual with schizophrenia, the essentiality of the care includes the acceptability of the treatment provided by the health care professionals and the social circumstances surrounding the service users, their caregiver and the entire family. This study identified care review, which includes engaging with the service users and/or their caregivers, meeting the needs of the service users and ensuring treatment availability for the service users, offers the opportunity for the mental health nurses and the mental health services to

monitor and manage schizophrenia well. All parties (service users, caregivers and nurses) must be transparent in their discussions with each other to elucidate the needs of the service users and offer strategies manage symptoms of schizophrenia. People around service users including caregivers and mental health nurses and encouraged to maintain open discussions about the service users, and promote their inclusivity, safety and privacy in the continuity of care. This study affirms previous study results of Bridges et al (2021) and shared decision making by Elwyn et al (2012/2017) which highlight the service user inclusivity by supporting them to make informed choices to improve their mental health.

The mental health service users' views concerning the care they receive are relevant. The Ghana's Mental Health Act 846 Section 40(2) (2012) encourages that service users consent before treatment is administered. It is, therefore, essential to seek the views of the service users in all matters concerning their care. This study supports other studies such as Anthony and Crawford's (2000), Siponen and Valimaki (2003) which advocate for active participation of service users in the process of reviewing and planning their care.

In reviewing care, the clinician must offer service users information about the care they receive. However, the service users are not obliged to consent to the aspects of care to be provided before the clinician can practically give care, especially, where service users lack capacity to consent to receive care. In practice, consent is not a single event and requires frequent discussions between the clinician and the service user, with or without their family. Marya (2022) contends that with long term care, consent becomes a recurring process. Marya's (2022) point is applicable where the treatment is offered for free. In Ghana, the observation from this study is that mental health treatment is largely based on the service user's or the family's ability to pay for the medication. Therefore, a family who is financially weak and cannot pay for the prescribed medication can hardly support treatment compliance for their relative diagnosed with mental disorders like schizophrenia. Service users from such families can benefit from free medication to ensure they receive treatment. These families must satisfy some conditions such as the level of income to determine those who can benefit from free medication.

The Mental Health Act 846 Section 96(f) (2012) indicates that the government is the main provider of mental health in Ghana. The Mental Health Services perform this function on behalf of the state. It therefore behoves on the Mental Health Services to review the care package the service user receives for the purposes of improving care for the individual. However, Rummery and Fine (2012) criticise the provision of care by the government as disempowering and suggest that service users lead the provision of care and support. Therefore, the review

must focus on symptom management which includes assessing the current mental state, effects of medication/treatment, physical, psychological and wellbeing, risk of self-neglect, risk of violence to self and others, effects of the medication on the service user, and social factors. The review meeting should include the caregiver and/or their representative. Mental Health Act 846 (MHA 846) (2012) Section 88 (1) indicates that mental healthcare is free and Subsection (2) states that a service user with physical health condition is entitled to free healthcare under the National Health Insurance Scheme. To benefit from the NHIS, the individuals must be a registered member of the scheme. The condition is that without a health insurance certificate, the service user must pay before treatment (Sarkodie, 2021; Nketiah-Amponsah & Sarkodie, 2014). MHA 846 (2012), subsection 2 states that physical conditions qualify for free treatment. Free mental healthcare entrenched in the Mental Act 846 (2012) is currently not implemented. In practice, the service user can only go for review/treatment if they had money to pay for the administrative charges such as getting their medical card/folder and most times for treatment at the point of care.

Being cognisant of the community service user living with their family members, it is imperative for the caregiver's health and social situation to be considered in tandem with the service user care review. This helps to improve the independence and wellbeing of the caregiver. It is critical to identify the areas for assessing the caregiver, which can include the effects of caregiving on the caregiver's health and wellbeing. All the community service users visited during the fieldwork lived with their families. This study did not gather data on all service users diagnosed with schizophrenia in Ghana. However, other studies indicate that service users living with mental disorders reside with their families and the family members care for their sick relative (Anderson & White, 2018; Rathod et al., 2017). About half of the people diagnosed with schizophrenia in Western countries and two-thirds of the service users in Asian countries receive care from their families (Wang et al., 2020; Peng et al., 2019; Yu et al., 2017). This study concurs with Peng et al (2019) and Yu et al (2017).

Although the caregivers and the service users live in large households, most of the households in the research enclave do not have any blood relations with the caregiver and service user; they are just co-tenants. In Ghana, there is a common practice of building big houses for extended families. Some members of the extended family may have migrated to other cities and big towns with similar types of housing. The houses may have many rooms for renting. This is how strangers can be living in the same big house sharing same kitchen and toilet facilities. With time, the co-tenants in a rented house, for example, become familiar with each other. Other co-tenants have no responsibility to take care of the service user. Therefore, the

caregiver bears the burden of caregiving with little support from the household. However, in the less urban communities, large families with blood relations living together is a common practice and they can support the caregiver to look after the service user. This is consistent with studies in other developing countries, which indicated that large families take care of the service user (Koc et al., 2020; Riley-McHugh et al., 2016; Talwar & Matheiken, 2010). In such communities, the caregiver is well supported by the people around them. In urban areas where the caregiver is far from their blood relations (extended relations), the care is mostly borne by the caregiver and their nuclear family, which becomes difficult for them. In such situations, it is expedient to consider interventions that will benefit the service user and the caregiver.

During fieldwork for this study, I noted an absence of a template for assessing service user needs. I also noted that support groups for service users with schizophrenia and their caregivers that are either client-led or professional-led would help improve psychosocial wellbeing of the beneficiaries. However, these were absent in the study enclave. Other studies for example Heller et al., (1997) identified peer-led family support and a psychoeducation, behavioural family therapy, and multiple family group therapy as significant programmes for the caregivers and service users. Therefore, the creation of services such as the mental health care resource centres, support facilities, and self-help groups (Angermeyer et al., 2003) is vital. Moreover, the creation of specific services such as home treatment, assertive outreach and crisis and early intervention teams consisting of different healthcare professionals (Kelly & Newstead, 2004) is crucial in offering the appropriate support for community service users and their caregivers.

The existence of support groups for the service users and their caregivers offers a strategy to make support practical. Factors of social support help to minimise the challenges that confront service users and their caregivers (Lu et al., 2023). Therefore, the uptake of the resources created to meet people's needs is necessary. The service uptake can enhance the demands of client-centred mental health care and resources (Lu et al., 2023; Yu et al., 2023), which indicates that mutual support in group therapy can be a buffer against stress for caregivers and their family members. In crisis, the information and instrumental support shared among family members could provide the understanding that pulling resources together is necessary to meet common family needs as found in this study and corroborated in Leffley, (1996), Chien et al., 2007; Lu et al., 2023, and Yu et al., (2023).

Care review as a need for the community mental health service user must be completed with the involvement of the caregiver. Therefore, the planning and treatment decisions must be agreed by the service user, the caregiver, and the clinician. This requires effective

communication with all stakeholders to facilitate better understanding of the care review process and arriving at better outcomes for the stakeholders.

In reviewing care, suggestions around connecting with others can be stressed when mental health services have resource centres and facilities for community mental health service users. This therefore requires an urgent attention to continue to enhance their lives as independent adults. They need their space to meet their peers and socialise in a protected environment that is managed by mental healthcare staff. The resource centre can have a library for their use. They can also continue to learn a craft for those who are willing to learn a trade. Moreover, day centres for games and other activities can be a laudable project for the service users.

Care review must be extended to the caregivers and their families to identify their current difficulties and signpost them to services that can offer guidance and training to boost their confidence to continue to support the service users but always maintain their own health.

### **6.3.1b: Health promotion for service users**

Promoting mental health and assessing the needs of caregivers, is based on participant experiences and forms part of the core findings of the investigation. The fundamental objective of modern caregiving is to foster the wellbeing of service users. This entails the coordination and facilitation of activities that are designed to enhance the physical, psychological, and emotional health of the recipients. The role of the clinicians, such as the nurses and psychiatrists, is to ensure that the service users receive care that is tailored to their individual needs and is delivered with the utmost professionalism and expertise. By prioritising the health of the service users, healthcare professionals can play a vital role in their rehabilitation and recovery, while simultaneously ensuring that their quality of life is fully maximised possible.

The study has uncovered the financial management challenges facing the Ghana Mental Health Service, which are mainly due to inadequate funding and poor infrastructure for mental health programmes. The consequences of this are that many patients are discharged to their families without adequate support (Awaf, 2016). It was reported about psychiatric nurses' strike due to lack of psychiatric medication and resources for the inpatient service (Okertchiri, 2016; Hussein, 2016; Ansah, 2016). Consequently, nurses have been compelled to request free psychotropic medication as found in this study. Another challenge is that nurses perceive health promotion for service users as primarily involving education. However, it is challenging

for a distressed service user to engage or cope with the health promotion programme meaningfully because they are not well and stable enough. The health promotion for service users must be perceived as activities for the benefit of the service users.

### **6.3.1c: Counselling.**

Counselling by and large has a subjective meaning (Rajagopal, 2013), however, it can involve a relationship between a professional and an individual plagued by problems which cannot be separately managed to aid the person in reaching solutions to address various types of personal difficulties (Nor, 2020). Therefore, counselling as support from the perception of participants, included advice as an avenue for conflict resolution and management and also, to prepare caregivers for the mentally challenging tasks of caregiving. For example, caregivers sought advice when dealing with the difficult behaviour of service users, which could be because of the symptoms of schizophrenia. Counselling, alongside a combination of other therapies, can offer strategies for managing issues related to service user and caregiver challenges. For illustration, Kamenov et al (2017) and von Wolff et al (2012) observed that combining psychotherapies with medication can lead to a better understanding of prognosis and lower relapse rates in schizophrenia. Counselling was identified as an effective means of providing psychoeducation and improving the wellbeing of service users, caregivers, and the public. Counselling is discussed as an integral part of the psychotherapy that is provided to caregivers.

### **6.3.2: Access to medication and treatment**

This nature or type of professional support for community mental health service users is very vital, given the poor resourcing of the mental health sector in Ghana (Rajkumar, 2022). Access to medication and treatment is vital for effectively managing schizophrenia, a severe mental illness, in Ghana. Ibrahim et al (2015) estimates that around 2.2 million individuals in Ghana are affected by mental disorders, with 650,000 of them diagnosed with severe mental illness. Therefore, investigating effective treatment approaches to support those living with schizophrenia is important. Hence, the assessment of needs for the service user must include medication compliance.

In assessing and diagnosing the mental illness, psychiatrists rely on the International Classification of Diseases version 11 (ICD-11) (WHO, 2022a) and the Diagnostic and Statistical Manual version V (DSM-5) (American Psychiatric Association, APA, 2022) to diagnose mental disorders based on the symptom(s) of the service users' experiences. The clinical explanation for mental disorder is psychological, social, and biological (Bolton & Gillett,

2019; Frazier, 2020; Poole 2021). The biomedical model proposes that mental disorders are fundamentally linked to brain diseases and places significant emphasis on pharmacological treatments aimed at addressing underlying biological abnormalities (Deacon, 2013). During the acute phase of the illness, hospitalisation may be necessary. The management of schizophrenia within mental health services primarily employs allopathic methods, particularly the use of antipsychotic medications. These medications become the first line of clinical strategy for treating schizophrenia (Chokhawala & Stevens, 2024; Markota et al., 2024; Walker et al., 2004). They reduce the impact of symptoms by regulating certain chemical messengers in the brain that can trigger the symptoms (Walker et al., 2004; Ginovart et al., 2012; Miyamoto et al., 2012; Sykes et al., 2017). The antipsychotics are an efficacious product for alleviating symptoms of mental illness. By incorporating antipsychotics into a treatment plan, individuals with schizophrenia can experience an improvement in their quality of life. Similar practice is encouraged in the research enclave when these individuals approach the mental health services for help. However, these medications carry some potential side effects (pseudoparkinsonism, dystonia i.e., uncontrolled and sustained intense muscle contraction/spasms, and akathisia i.e., restlessness), and therefore require monitoring by clinicians (Chokwala and Stevens, 2024).

In practice, antipsychotics are not free in Ghana (Oppong et al., 2016). The entire mental healthcare service has acted in contravention of the Mental Health Act (2012) 846, which supports mental health services' operations.

The barriers to the use of antipsychotics, including side effects of medication and the scarcity of mental health services in rural areas provide the motivation for those with schizophrenia to seek help from traditional healers and faith-based services, as the first step of seeking help. In Ghana, access to mental health services in rural areas is severely constrained, with most services concentrated in urban areas (Badu et al., 2018; Robert et al., 2014; Nartey et al., 2019). These challenges impact significantly on the effective treatment of mental health disorders in rural settings. Therefore, individuals with mental illnesses access help from the faith-based and traditional healers in Ghana (Ofori-Atta et al., 2010).

Access to formal treatment is available in Ghana and it is based on a biomedical model of health. The available antipsychotic medications have proved to be effective but have side effects. Aside the biomedical model, individuals practice traditional medicine which includes spiritual healing and the use of herbal medicine. Therefore, biomedical and traditional medicine are practised concurrently.

#### **6.4: Objective 3- To investigate the nurses' experience of caregiving in the community setting.**

##### **Theme C- the experiences of nurses providing care in the community mental health setting.**

The experiences of nurses providing care in the community mental health setting are discussed under nurses' experiences of caregiving and addressing the challenges facing mental health nurses. The experiences of nurses in their provision of care to service users is impacted by the individual, interpersonal/family, organisational/institutional and community and policy domains of the EMHP. This is because these experiences cut across all these domains in the operation of their work.

##### **6.4.1: Nurses experiences of caregiving**

The commitment of nurses to their organisation and their roles remains the essence of the nursing profession. The community mental health nurse's work is not at the top-level of management, but it is important for the community where the service user and their caregivers are based. The community nurses' main work is in the setting outside the hospitals, and their interaction with the community is paramount. It is relevant to discuss engagement as the main tool for their performance. The qualified nurses' interactions with the caregivers, the people diagnosed with schizophrenia and the entire community indicates a special position they occupy in helping to manage schizophrenia in the society. This position is dictated by policies from the Ghana Mental Health Authority- i.e. government laws and regulations, and in theory nurses are expected to engage at the highest level (the eight rung) of the ladder of citizen participation, where service users have 'citizen control', that is a large degree of inputting into their care plan. However, service users are usually engaged at the lower levels of the ladder due to their disability, inadequate service provisions due to funding and related resourcing challenges like trained staff and transportation. This relationship, therefore, permeates most aspects of community mental health service provision in the country. This study found nurses' experiences of caregiving to include counselling, care review and access to medication, and advocacy service for service users.

This section will deal with the nurses' experience from the context of challenges facing the mental health services in Ghana to the lack of free psychotropic medication for service users, irregular staff training, stigmatising attitude towards mental disorder, and transportation

problems for mental health nurses. These challenging or disorganised experiences are discussed below.

#### **6.4.1a: Lack of free psychotropic medication**

As noted already in Section 6.3.3 (Access to medication and treatment), the law governing community mental health services in the study region make provision for the prescription and the administration of antipsychotic medications. However, some nurses observed that community service users can only access these medications by paying out-of-pocket. The service users can go for review and obtain a prescription, but since the mental health services run a cash-and-carry system, the individuals can only obtain the medication when they pay for it. They can purchase the medication from the hospital pharmacy or in retail community pharmacies. This observation confirms studies by Woebong et al (2023) that there is inadequate access to free psychotropic medication.

The community mental health services at district hospitals and health centers are overseen by mental health nurses. Even though clinicians are able to prescribe psychotropic medications, these are not available for free in the study area. As intimated in the literature (Oppong et al., 2016, Duxbury et al., 2010), psychotropic medication becomes the bedrock of mental health treatment in secondary care settings. Therefore, the mental healthcare service cannot run without the use of medication. In practice, nurses are identified with administering antipsychotic medications.

Furthermore, Role theory requires that service operatives (formal roles) or family members caregiving for the service user engage in the roles they have accepted to perform. Whereas formal roles of service user care may be defined, the social care provided by the family and outside the health environment is undefined, but caregiving requires that performers of the services need to relate with others, be they service users, other healthcare practitioners or family members to ensure the needs of the service user are met in the community. This makes the roles of the qualified community mental health nurse and the family caregiver complementary in their attempt to provide the relevant care services for the service user recovery. The service provided would focus on the preventive, therapeutic, and buffering roles of formal and informal networks of social care to ensure successful role performance and adjustment of service users and their families (Bowen, 1998; Bowen, Martin, & Ware, 2004; Flake et al., 2009; Orthner & Rose, 2009).

For the mental health service as an organisation, it is imperative to define job and person specifications for a qualified mental health nurse working in the community mental health service. Gray and Pratt (1989 and 1991) contend that there is a considerable effort by the

nursing profession to develop role statements or describe nursing by task or job analysis. However, a definitive description of community mental health practice has not evolved. In the course of my fieldwork and visits to the National Headquarters of the Mental Health Authority and a regional office, it was difficult to access any specific documentation on community mental health in general and community mental nursing in particular. Understandably, this is a service that is emerging in the country, and it is plausible the authority is in the process of defining the specifications and expectations of the community mental health nursing practice. However, Osei (2016) notes the role of mental health nurses in the mental health delivery algorithm as the authority's vision. Osei further posits around the workflow that the community mental health nursing is organised at the sub-district level. This is where the professional mental health nurses can be located to deliver services to the respective service user groups. Much as the work flowchart depicts the nursing position the professional nurses perform slightly above other groups of community workers who are volunteers, traditional healers, community mental health officers and non-governmental organisations who are immersed in the community mental health work. In the research location, professional mental health nurses work in both primary and secondary mental health services. Integrating primary and secondary healthcare services is recommended by the World Health Organisation (2020) and this is commonly practised in the community mental health services in Ghana. The qualified mental health nurses working in the community oversee a specified catchment area.

The behaviour of the professional mental health nurse depicts their engagement with others either under their care or not. Thomas and Biddle (1966) postulate the consistency of but differentiated behaviour in role performance. These differentiated but consistent behaviours help define the specialisation associated with the role performance. As professional nurses with specialty in dealing with mental disorders, their role involves executing many functions in supporting people associated with the field of mental disorder. The Mental Health organisation worldwide has numerous functions (differentiated functions) which include developing policy, providing services, promoting mental health among the citizenry and promoting multiagency working and research (World Health Organisation, 2020). The professional mental health nurse engineers the opportunity for allowing the organisation to interface with the community. In so doing, the community mental health nurses are charged by their employer to ensure the interface with the community. Therefore, it is the responsibility of the qualified mental health nurses to maintain a consistent approach to performing the roles they are charged with that demonstrates their professionalism. It is no surprise therefore for all the qualified nurses interviewed to identify for example, "visitation" as one of their duties they must perform. Visitation is a means by which the qualified community mental health nurses adopt to enable engagement with their service users and their families, and the rest of the community. Apart

from visiting to administer treatment prescribed by the psychiatrist who is based at the hospital environment, the community mental health nurse monitors the mental state and the general functioning of the service user outside the hospital environment and facilitates mental health education in the community through engagement with targeted groups in the community such as market women, taxi drivers and food vendors. Again, this study identified the promotion of the mental health of pregnant and new mothers as another important role of qualified mental health nurses. The proactive approach to promote the mental health of the community dwellers is deemed one of the most important services carried out by the mental health nurses in the community settings. The settings include chapels, schools, marketplaces and open places in the community. One of the interesting sessions observed was when I observed a session led by two mental health nurses facilitating learning for a group of 12 men who were playing draught under a big mango tree. This was described as a way of reaching out to the public at the basic level because the catchment area did not have any mental health voluntary organisation engaging with the community from the grassroots. The differentiated roles of the mental health service are further shown in Castillo et al (2019).

The community mental health nurses require regular training and workshops to keep them abreast with changes that are introduced in the mental health services. The nurses require refresher courses that can help them increase their store of knowledge in their roles and improve their skills. During fieldwork and data gathering, it was noted that staff training was neglected. Training on Mental Health Law and Risk Assessments for nurses were found to be lacking in this study. This study echoes a previous study by Angermeyer et al., (2003) who found knowledge about mental health care legislation is relevant. Organising seminars and workshops to facilitate understanding of the importance is likely to build a service manned by people who are willing to make a change. The adage is that knowledge is power. A knowledgeable workforce is a powerful workforce ready to provide quality results for the service.

#### **6.4.2: Addressing the Challenges Facing Mental Health Nurses**

From the experiences of nurses, several challenges were noted. Participants offered ways of resolving the challenges they observed in their roles within the community mental health services. All the nurse participants indicated, various propositions for addressing the identified challenges. The propositions included providing free psychotropic medication; staff training; adopting inclusive mental health service; and tackling transportation problems for nursing staff

associated with the community mental health services. These identified themes are discussed individually below. Each theme has examples drawn from the semi-structured interviews with the nursing staff.

#### **6.4.2.1: Free psychotropic medication**

Psychotropic medication remains the critical intervention for schizophrenia. For example, this study highlights medication for addressing the clinical needs of the individuals diagnosed with schizophrenia (Bruijnzeel et al., 2014; Oppong et al, 2016; Nartey et al, 2019).

The importance of antipsychotic medication has been underscored by this study, as one effective way of managing the disorder. Service users who attend reviews place significant value on medication. Both nurses and service users have expressed a positive perception of medication, citing its helpfulness in managing symptoms. Participants argued that the service users cannot access free prescribed medication from any pharmacy - state hospital or private. This is confirmed in a study by Al-Ruthia et al (2017), as they noted that antipsychotic medication was not free, which meant that some service users diagnosed with serious mental illnesses who could not afford medication tended to relapse.

This study found that there is a prevailing issue with free accessibility of psychotropic medication. The nurse participants in this study discern the gravity of this challenge, and they have expressed their utmost concern regarding the lack of free medication for service users. It is their contention that this situation makes it arduous to monitor their treatment effectively. In light of this, it can be argued that it is of paramount importance to find a viable solution to this issue, as doing so will undoubtedly serve to enhance the quality of care they provide to their service users.

Mental health practitioners are concerned about the costs associated with accessing mental health treatment. Thus, in trying to address this issue, Ghana's mental health law, Act 846, (2012) directs that mental health services should be provided free of charge (Section 66, sub-section 2) and individuals registered with the National Health Insurance receive cost-free healthcare. However, concerns persist regarding the execution of mental healthcare regulations for individuals diagnosed with mental disorders, who are still required to pay for their medication. For instance, in mental health facilities, access to antipsychotic medication is essential. However, many caregivers and service users face financial difficulties and struggle to afford their prescriptions and hospital bills. This often results in non-compliance

with treatment, particularly among those from low-income families (Lovell, 2024). To make treatment more affordable, one would expect that the government's social intervention programme (National Health Insurance Scheme, NHIS) would offer community mental health services a financial pool for service users and their families, but this is not the case, and this contradiction of not providing free mental treatment is noted (Yaro, 2023).

Advocating for free medication to treat mental illness must be dependent on the availability of the commonly used psychotropic medication in the research enclave. Moreover, such medication must be monitored carefully to ensure that the medication goes to the person intended for. In the absence of free medication, heavily subsidised psychotropic medication would help encourage concordance among the community mental health service users in the research study enclave. To address this concern, community mental health nurses suggested that mental health treatment be made available free of charge to service users in the study area. The goal is to ensure that those who require treatment can access it without financial barriers. For families with limited income, the expense of mental health treatment can be a considerable financial strain. Offering treatment free of charge may ensure the low-income service users and families could have access to the medication without difficulty. Thus, hospital pharmacies could be the main point of supply of the free medications to the service users.

#### **6.4.2.2: Staff Training**

Staff training is important for the mental health service to improve skills and staff performance, and this is impacted by the organisational/ institutional, community and policy domains of the EMHP framework. Thus, the mental health nurse participants interviewed for this study observed that training is the way forward to helping them improve on their role due to gaps in their knowledge and skills (Jabbie et al., 2023). Recognition of providing training is indicative of ensuring that human capital is available to drive the institution's agenda that seeks to promote and maintain quality mental healthcare.

Training offers new knowledge and skills to nursing practice as it offers information about new techniques to new approaches to assessing needs. It helps the mental health services maintain employees with current knowledge and confidence in their practice. It is therefore advocated that all courses must be attended by nurses free of charge and must be certificated to show proof of completion. Training contributes to the proficiency required of staff to perform their role and positively impact the mental health service as an institution. The knowledge and

skills they acquire through training allow the staff to be more productive and perform better quality work (Rodriguez and Walters, 2017).

Although nurses are trained in colleges and universities, and understand their roles and responsibilities, the nurses value refresher courses as an important ingredient to their continuing professional development (CPD) and training organised by the employer post-registration and when they have started practising. As an institution, the mental health service has targets to meet. Training must therefore equip the staff with the relevant knowledge and skills to meet the changes that are introduced within the institution.

#### **6.4.2.3: Solving Transportation Problems.**

In order to visit service users in their homes, community nurses are often confronted with unpredictable weather conditions. Given that many of these healthcare professionals don't have their own means of transportation, they must rely on public transportation and walking to complete their journeys. For instance, transportation was seen as a basic but essential requirement for providing health care and medication access, principally for those with chronic diseases in remote areas (Syed, Gerber and Sharp, 2014), and was true in the area of the study, and therefore a barrier to access community mental health services. In interviews for this study, mental health staff nurse participants offered suggestions for addressing these transportation-related challenges.

A suggestion for remedying this situation which was also noted by participants included the payment of transport expenses as a potential solution to the current issue. For example, establishing a structured system for reimbursing transport expenses for mental health nurses during their visits to service users and organisations. Non-payment of business travel expenses can be demotivating for the community mental health nurses in performing their roles in the community. In accordance with their responsibilities, the provision of transportation benefits/expenses could prove advantageous. The nurses do not have to worry about the payment of their expenses which can encourage them to continue regular visitations to the service users and other community outreach programmes. The parity of payments of these expenses across the community mental health nurses' roles is necessary to minimise disenchantment among the workforces. Therefore, business travel expenses must be paid by the central government to ensure a fair system.

Although the use of digital technologies can bridge social and physical distances, such as was the case during COVID-19 (Galea, Merchant and Lurie, 2020) between nurses, service users and caregivers, this is not always possible in Ghana because digital technologies are not in place, thus transportation remedies this problem. The provision of staff buses and motorbikes for the community mental health staff is suggested as another intervention to be considered by the government. The bus can be used to transport nurses from the office to the places they are to interact with the public and near the homes of the service users. It will curtail the payment of transportation expenses that the nursing staff incur in line of duty. Using the bus can reduce delays in travels to and from service users and other public engagements the nurses would engage in. The nurses do not have to wait for the public transport to load up before leaving the terminus in addition to passengers being dropped off certain points of the journey.

The above-mentioned strategies offer suggestions for addressing the challenges identified by the nurses. The solutions offered here are free psychotropic medication, staff training, adopting a more inclusive mental health service, and addressing transportation problems in the study enclave.

#### **6.5 Objective 4- To investigate the services the caregivers of community service users are currently receiving and to establish what they consider to be appropriate support in the community.**

##### **Theme D- the services provided to caregivers and their suitability.**

The appropriateness of support given to caregivers in the community, are to a large degree influenced by the EMHP domains of individual, interpersonal/family, organisational/institutional, community and policy support. It is however worth noting that the organisational/institutional domain has a disproportionate input in the type of support that is given to service users and caregivers. For example, nurses were noted in this study to be offering only the support that was in their power. Thus, in cases where medication administration was urgently needed, nurses could not administer medication to service users they were caring for to help caregivers manage them, because the medication was not available. This was in the light that medication had to be provided by the service user and their caregivers. These constraints were by and large, determined by institutional challenges, such as inadequate resourcing. Therefore, even though caregivers could exercise a large degree of autonomy and control over their care in theory, that is at the level 8 of the participation

ladder (Arnstein, 1969), they could not effectively challenge the type and suitability of the care they were getting.

### **6.5.1: Services caregivers receive from community mental services**

Community mental healthcare services during the study were expected to provide caregivers with an array of services or support. This is in the light that caregiving is tough, and generally, the caregiving role in the community is commonly occupied by family members of the service user who is the recipient of the care provided (Chiao, et al, 2015). However, support services for caregivers from community mental healthcare services were virtually absent. There was an absence of respite care, which participants suggested as an essential support service that caregivers needed, thus the absence of such support resulted in the fatigue in caregiving and there were no suitable services offered to caregivers.

For example, In the context of Ghana, the caregiver and their families constitute a major resource (support service) for the service users with schizophrenia and are under the community mental healthcare service. Population growth and longevity have increased because of advancements in global health. Life expectancy increased from 65.3 years in 1990 to 71.5 years in 2013 (Murray et al., 2015). As people live longer, the population grows older. It is estimated that people aged 60 and above would increase from 12 to 22% by 2050 and will need support for activities of daily living (WHO, 2024). Caregivers are likely to grow old and must be supported to enable them to continue to offer practical support to the family members diagnosed with schizophrenia.

In this context, the overarching view of this section is to explore the services the caregivers of community service users are currently receiving and the appropriateness of this support. Since the introduction of decentralising Ghana's Mental Health System from 2000 (Asare, 2010), most of the community service users diagnosed with schizophrenia live with their families. By the nature of schizophrenia, the service user requires continuous support from family members because of the difficulty in managing themselves. They are unable to accomplish common life roles and necessitate interminable care from the caregiver and their families (Neller et al., 2024; Bademli et al., 2018). There is no doubt that the caregiver plays a relevant role in supporting the service user in the community (Bademli et al., 2018). The caregiver and their family involvement in the care of service users with long-term conditions such as schizophrenia offers a dialectical opposition between positive and negative experiences of support during the care for the sick relative and can be both demanding and rewarding. The mixture of outcomes, positive and negative experiences, are the caregivers' appraisal of their

situation in respect of caregiving. Therefore, their interpretation of things they do and receive becomes very important. This study agrees with Chiao et al's (2015) study which concludes that caregiver burden defies a single factor. Chiao et al (2015) further suggest that healthcare professionals provide support appropriate to reduce caregiver burden. The current study also confirms Awad et al's (2008) review of burden of schizophrenia on caregivers. Awad et al (2008) found that the caregivers were distressed.

This study reveals that Ghanaian families involved in the treatment process of mental disorders are tolerant and supportive. Caregiving for a family member diagnosed with schizophrenia necessitates time, energy, and money from caregivers. Caregivers provide these elements of support throughout the trajectory of the mental disorder. The caregiver engages in physical work and endures emotional and social pressure in their bid to offer support to the service user. The caregiver participants in the current study spend considerable hours providing support to the service user. This includes providing therapeutic observations to the service user to minimise the risk of leaving home and assaulting a member of the public or wandering about without any purpose. Therefore, the severity of risk posed by the service user necessitates closer observations by caregiver and restricts the caregiver from engaging in activities that can bring income to the household. Therefore, providing care for others can be a daunting task, taking a toll on one's physical and emotional wellbeing. Caregivers often grapple with negative feelings such as anger, dissatisfaction, guilt, frustration, tension and family conflict (Broe et al., 1999). This can be an especially difficult situation for those caring for individuals with severe mental illnesses. Consistent with Di Lorenzo et al., (2021), the severity of the mental disorder determines the burden of giving care to the service user. However, the caregivers who do not live with their service users are less concerned with the day-to-day physical aspect of caregiving. The severity and chronicity of the disorder requires collective and comprehensive caregiving, which can amplify caregiver emotional burden (Stanley et al., 2017; Ong et al., 2016). Other studies such as caregiving in palliative care and terminally ill service users (Zavagli et al., 2016), in stroke service users (Camak, 2015), in dementia care service users (Grover et al, 2017) confirm that irrespective of the disorder of the service user in the family, the caregivers are overburdened with looking after the sick. The different conditions noted in the studies portray that serious conditions can be challenging for the caregiver. By extension, caregiving in the management of schizophrenia among community service users becomes more challenging for the caregiver and the family when the disorder is chronic.

As a chronic condition, schizophrenia demands both physical and psychological resources of the caregiver and the family to maintain the service user at home. The caregiver requires resources such as time, energy and money to continue to offer support to the community service user. Though, respite care and addressing the fatigue in caregiving were suggested by the study participants, these however, were challenging to negotiate by caregivers and community mental health staff, and are discussed below.

### **6.5.1a: Respite Care**

Study participants were of the view that service users needed respite care. This was seen as a vital means of helping caregivers cope with the stresses of caregiving, because it allows them to have time off or take a break from their caring duties, as service users are cared for, for a brief time by other professionals or other persons (Helping Hands, 2024). Although Respite care was essential because it enables emotional and physical refreshment for the caregiver this was hardly provided in the study area for caregivers for several intersecting reasons. For instance, the chronicity of schizophrenia means once the person becomes unwell, they require support. The nature of the disorder means that support given in the past must continue throughout the lifetime of the service user. The caregivers must continue to offer their support to ensure the service user lives optimally and functionally in the community. The tasks performed in the process of offering support are continuous.

The caregiver monitors the safety of the service user and their general wellbeing at home. All these activities that demand caregiver's time can add to their burden of giving care to the service user. Sacrificing time to give care to the service user is vital, therefore the caregivers does not have time for respite themselves. This is because the caregiver participants in this study revealed that their presence and monitoring of the service user at home helps the service user's recovery. This study suggests that the caregiver spends time to perform activities such as food preparation and administration of oral antipsychotic medication to ensure treatment compliance. This finding is in line with other evidence suggesting the importance of caregiver role in administering pharmacological treatment for mental disorder because service users frequently portray poor adherence to therapy (Lacro et al, 2002; Haddad, Brain, and Scott, 2014).

Thus, assessing the quality of life of caregivers using Health-Related Quality of Life, caregivers of family members diagnosed with schizophrenia were found to be more burdened than their counterparts giving care to other service users with chronic medical illness (Di Lorenzo et al.,

2021; Gupta, Isherwood, Jones, Van Impe, 2015). This study reveals that caregivers have less time for other social activities that take them out of the home or respite care to offer them space to focus on themselves.

For caregivers who struggle to find time for themselves, this suggests that the condition of the individual they care for is not in remission, yet they are still managing their care at home. Rahmani et al (2022) and Kate et al. (2013) highlighted that efficient management of the service user's symptoms resulted in a reduced demand on caregivers regarding time and the strain on their coping abilities. Consequently, this alleviated the subjective burden and psychological distress experienced by caregivers. This therefore suggests that caregiving can be associated with poor quality of life if not properly managed. This study also confirms the works of Zarit et al (1980/2001), and Qiu et al (2023) - a Chinese study- which also link caregiving to psychological problems/mood disorders such as stress, anxiety, and depression.

Whereas the caregivers in this study do not have any working time directive, healthcare workers in the formal setting have defined hours of work with time allocated for recreation and rest. There is the established 48-hour week and eight-hour day and implied support for the weekly rest principle (The International Labour Organisation, 2018). The quantum of hours worked, and the length and number of rest periods are defined in the formal sector for the employee and the employer in the employment relationship. However, in the case of the caregiver providing support for the service user in the community there is no such arrangement for them.

### **6.5.1b: Fatigue in Caregiving**

In addition to time, energy and money are expended in caregiving constitute sources of caregiver burden (Zhou et al., 2021). Thus, it requires managing these stresses of caregiving (fatigue). For instance, apart from spending time to support the service user in the community, the caregivers also invest their energy giving care to the service user. They spend energy in helping the service user to meet their specific needs in terms of performing domestic chores such as culinary activities, tidying up their home environment, and helping to maintain personal hygiene needs among others. These physical activities can lead to physical exhaustion. In the current study, most of the caregiver participants identified physical activities as time consuming and tiring. The caregiver participants assume additional responsibilities at home to make life less difficult for the service user. This evidence confirms that long-term caregiving results in feeling tired and weak due to the activities involved in caregiving (Caicedo, 2014;

Lollar et al., 2012). Arguably, the quantum of physical activities completed can cause caregiver fatigue which minimises their physical strength.

Caregiving involves expending energy to execute physical activities in offering support to the service user. In executing the tasks inherent in support, the caregiver can be fatigued, the caregiver has little energy for other activities, but they feel compelled to continue to support their service users. The general sense of the study suggests that caregiving for a person with schizophrenia is associated with fatigue mainly because of the irregular hours the caregivers work. This study supports a Chinese study (Chen et al., 2019), which found that most caregivers assumed extra responsibilities and did excess housework, when providing support for their service users diagnosed with schizophrenia. Moreover, the current study reinforces more than two decades old assertion by Harrington (2001) that caregivers who work abnormal hours feel fatigued.

Caregiving exacerbates the caregiver's low energy. As caregiving tasks increase, caregivers may develop high risks of fatigue and frailty (Potier et al., 2018; Wennberg et al., 2022). Physical and mental stress are linked to providing care. Tiredness, becoming physically weak, and having less energy to perform domestic chores portray an element of poor lifestyle for the caregivers. On the contrary, the same physical activity can be used to build physical strength. Much depends on the caregiver's approach to performing the tasks. For example, planning the chores to be completed and allotting time with breaks to ensure they do not work themselves down must be encouraged. Being exhausted does not augur well for the health and wellbeing of the caregiver. In this light, activities that are focused on building the strength and improving the health of the caregiver is encouraged. A study suggested that structured physical activities improve people's health and reduces their burden (Dhuli et al., 2022; Lok et al., 2022). However, the caregivers in this study did not identify any structured physical activity programme that was available or provided by community mental health services to improve their quality of life. It stands to reason that structured activities targeted at improving caregivers' burden and health provide the intended outcome. For example, offering caregivers leisure time adventures to undertake physical activity could offer improvement in dealing with emotional problems. A study in the United Kingdom found physical activity can reduce symptoms of depression and anxiety (Bell et al., 2019) and exercise may improve health and wellbeing of caregivers (Noetel et al., 2024; Hawken et al., 2018). Also, a study among Japanese caregivers' population found that an increase in physical activities, particularly recreational activities for the caregivers, reduce caregiver burden (Hirano et al., 2011). However, in the case of this study, since the service users are always at home with the

caregivers, it becomes difficult for the caregivers to focus on recreational activities as it was in the Japanese study. The health and quality of life of caregivers may be improved by interventions that can help manage their physical activity levels efficiently.

Hence, programmes to educate the caregiver such as time management, planning their chores and taking regular breaks would help them to manage their day and to better structure physical activities to minimise the strain and stress associated with the care they give. The service users who live with their families need the support of their caregivers to enable them to live their normal lives in the community. Absence of the family support would put many service users' lives in despair in Ghana. Currently, there is no agency that seeks to promote the social needs of the service user diagnosed with schizophrenia or that of their caregivers in the Ghanaian society. The caregiver and their families are left with many responsibilities to fund the health and social needs of the service user, which contribute to the caregiver burden. Whereas other studies found planning and execution of activities offer health benefits to the caregivers, the current research found no evidence that either service users or their caregivers took part in regular physical exercise other than walking.

### **Summary:**

This chapter discussed the findings which were conceptualised as themes of the study also using the conceptual framework of the EMHP (McLeroy et al., 1988), together with Arnstein (1969). These discussions are therefore situated in the larger context of the aim and objectives of this study. This study has explored the support given to people diagnosed with schizophrenia and their caregivers living in Ghana.

The findings or main themes covered:

(a) the perceived meaning of support for service users - physical and psychological support were identified as forms of support by participants.

(b) the nature of professional support for community mental health service users - this entailed delving into emotional support, counselling, care review, access to medication and treatment, and health promotion.

(c) the experiences of nurses providing care in the community mental health setting - these were several, and covered counselling, care review and access to medication, and advocacy service for service users.

(d) the services provided to caregivers and their suitability - there was an absence of support for caregivers and this was discussed in the context of respite care and fatigue in caregiving.

These were critical issues due to their impact on caregivers and indirectly on support for service users.

(e) the challenges facing community mental health services – these came in the form of nurses' experiences of caregiving, with subthemes such as counselling, care review and access to medication, and advocacy service for service users. The other main finding under (e) was addressing the challenges facing mental health nurses, which also entailed the discussion of subthemes such as: providing free psychotropic medication, staff training, adopting inclusive mental health service, tackling transportation problems for nursing staff associated with the community mental health services.

Finally, in the discussion for this particular study, it emerged that support was conceptualised differently. Caregivers did not get the support they needed from community mental health services. Added to this, several challenges plagued the mental health services, from the absence of free psychotropic medication to difficulties in the provision of transportation for nurse. Although some resolutions were presented, they are not likely to see the light of the day, in terms of them being addressed by the government imminently.

# **CHAPTER SEVEN: RECOMMENDATIONS AND CONCLUSION**

## **7.1: Introduction**

This study generated understanding and knowledge regarding the support given to service users diagnosed with schizophrenia and their caregivers in Ghana; in doing so, the study highlighted a number of challenges that needed addressing in policy and practice. Therefore, this chapter reviews the objectives and the research question of this study. This is followed by recommendations to the stakeholders for improvement to policy and practice in Ghana. The implications for policy and practice, which is presented as Objective 5 - will therefore be discussed. This study also discusses the contribution to knowledge.

## **7.2: A review of the research question**

The research question was: How are the service users diagnosed with schizophrenia and their families supported by the community mental health services in Ghana?

The community mental health services supported service users diagnosed with schizophrenia by reviewing and assessing their mental state, prescribing treatment, administering psychotropic depot injections, monitoring the effects of medication and providing emotional support. In the case of families who are also caregivers, support referred to the services provided by mental health services to the service users. This included treatment prescribed to service users, administration of depot injections, counselling, public health/health education and visitation to reduce travel expenses to families. These were placed in the larger context of the objectives of the study. However, how service users diagnosed with schizophrenia and their families were supported, experienced a number of challenges, such as the lack of: free psychotropic medication, respite caregivers, and also caregivers' assessment to determine their needs.

### **7.2a: Objective 5 -To make recommendations concerning policy planning and implementation to enhance the provision of community mental healthcare service in Ghana.**

The study identified several issues plaguing the support given to people diagnosed with schizophrenia and their caregivers living in Ghana. Therefore, recommendations for areas

requiring policy planning and support implementation are discussed in more detail below under the following headings: policy reform; free psychotropic medication; the value of caregiver group support; transportation for nurses; resource centres; review of education and training for nurses and, mental health crisis teams.

### **7.3: Policy planning and implementation.**

Policy planning and implementation in this context refers to the policies and practices outcomes as intended by the Ghana's Mental Health Act 846 (2012). This study generated understanding and knowledge regarding the support given to service users diagnosed with schizophrenia and their caregivers in Ghana. In doing so, the study highlighted a number of gaps that needed addressing in relation to the policies. Therefore, this study has contributed in diverse ways to knowledge on policy and practice. This is because the literature reveals a paucity of evidence on social health policy for the service users in Ghana that support and actively promote social inclusion. For example, an assessment of mental health policy of Ghana, South Africa, Uganda and Zambia notes that the policy partially mentions social inclusion (Faydi et al., 2011) and does not vigorously advocate for 'real' support for service users and their caregivers.

#### **7.3.1: Policy Reform: with regards to caregivers' assessment**

Conducting this research study has led to the discovery of areas of significant contribution to knowledge. Firstly, the literature review on policy and legislation established a paucity of evidence concerning caregiver needs assessment in Ghana. For example, Act 864 does not provide any information and justification for caregiver needs assessment. Therefore, the mental health service does not provide any specific service to the caregivers. This study identified that caregiver needs assessment is highly relevant. Consequently, it highlights the significance of caregiver needs assessment and advocates for its integration into mental health practice across the country.

Therefore, policy reform pertaining to caregivers' assessment for establishing clear boundaries around the responsibilities of individuals, families, and the government is essential. Although family caregiving for individuals with schizophrenia is a private matter, it also holds significance as a societal concern. From an individual's standpoint, providing care for a sick relative is partly a personal or family responsibility. Family caregiving represents a

critical public policy issue. This study emphasises the necessity for reforms in policies and practices affecting the role of families in providing support and care for individuals diagnosed with schizophrenia. Recognising and supporting family caregivers is integral to the government's collective responsibility in caring for individuals with schizophrenia.

### **7.3.2: Free Psychotropic Medication**

The study highlights the challenges faced by caregivers and identifies gaps in policies and practices for individuals with chronic severe mental disorders. The lack of free or heavily subsidised psychotropic medications is a major concern, and the provision of such medication is crucial for upholding the rights of service users. Their rights include the right to available, accessible, acceptable, and good quality care (WHO, 2023), which involves the supply and administration of medication. This study recommends that policy makers should review the National Health Insurance Scheme to cover psychotropics and to ensure that all mental health service users are registered under the scheme.

The Social Welfare Department should conduct a social circumstances report on each service user to determine those who need financial support, particularly for medical bills. Mental health units should be staffed with at least one mental health specialist social worker to conduct the social circumstance report for financial support. The government can establish a special fund for mental health services, and revenue can be generated through special taxes to fund mental healthcare delivery in the country. The ministry of health should ensure that the revenue is not misappropriated. Policies about the special fund should be designed to limit funding only to medication that treats the mental health service user, specifically psychotropics. This study emphasises the need for free psychotropics to be made available directly to service users or to their caregivers.

One way to alleviate the difficulties in accessing psychotropic medication for managing mental health symptoms is to provide service users with free medication. Currently, the National Health Insurance Scheme only covers physical health medication, but it can be extended to encompass psychotropic medications for individuals who require mental health services. By extending the National Health Insurance Scheme, individuals with mental disorders can receive the support they need to manage their symptoms effectively.

### **7.3.3: The value of Caregiver Group Support**

The study indicated that caregiver support groups did not exist. This lapse needs addressing through policy formulation. For example, the existence of a group of caregivers to support each other is necessarily to promote their emotional or psychological and physical wellbeing. The group can present a strong voice to negotiate for their identified needs to be met. For example, support in the form of psychotherapy. Psychotherapy is a crucial resource for maintaining good mental health, and it is important that both caregivers and service users have access to it.

Additionally, mental health services can facilitate the formation of peer groups among caregivers, where they can come together to discuss daily challenges and work collaboratively to find solutions. These groups can provide a supportive environment for emotional encouragement and collaborative problem-solving (Marshall et al, 2024). Advocacy or peer groups enhance service reviews and is a direct consequence of collective action at mental health centres. When unified, peer groups, service users and caregivers wield significant influence in evaluating mental healthcare delivery and in shaping policies related to care provision for mental health issues. They are a potent force in the planning and execution of mental healthcare policies.

### **7.3.4: Transportation for nurses**

For nurses, reliable transportation is a critical component in ensuring they reach healthcare facilities in good time for their shifts. Whether they work in hospitals, clinics, or community settings, having dependable transportation enables nurses to fulfil their work responsibilities promptly and efficiently.

The community mental health nurses understand that their work is in the community. They facilitate health promotion programmes outside their office base. They are peripatetic clinicians whose work can be aided with means of transportation to help travel from their base to the service users and their families. Mental health services can arrange to transport the nurses to the points of delivering care and return them to the office.

The community health nurses require transportation that is both reliable and efficient. This is because it allows them to conduct home visits, provide care to patients in their residences, and reach remote areas where patients may require medical attention. It can alleviate the stress associated with commuting, allowing nurses to focus on service user care without worrying about transportation issues, traffic delays, or the reliability of their mode of transport.

Reliable transportation is indispensable for community nurses, impacting their ability to provide timely care, reach patients in various settings, and navigate the demands of their profession. Ensuring accessible and efficient transportation options for nurses is essential to support their crucial role in healthcare delivery.

### **7.3.5: Resource Centres**

Facilities such as resource centres for community mental health service users in the research enclave like in many other areas of the country were non-existent between 2016 and 2022. The inpatient service users have a workshop where they can go to learn a craft. When they are discharged from the mental hospital, there are no resources to take up, especially for those who are not working. Identification of challenges in the policy document is an attempt to advocate for provision of resource centres to enhance social inclusion of the community mental health service users and their caregivers. The healthcare service must show leadership in the provision of care by ensuring social health facilities are established to support healthcare services.

It is recommended that the community mental health service should have in place, resource centres which are well-funded. A day resource centre is a beneficial facility for service users to undertake activities and enhance their social connections. It provides a safe haven for individuals who have no other place to go, offering them the chance to engage with peers and participate in meaningful individual and/or collective activities. These centres offer a platform for service users to support each other and develop stronger social bonds. Spending time in a secure and therapeutic environment can help individuals learn positive coping skills and manage themselves better than in their homes. By interacting with others, service users can improve their social skills and alleviate loneliness, which can worsen mental health conditions. The therapeutic activities can include activities such as games, art and craft, and a library, for instance to encourage service users to engage better. Also, the centres can have other support groups such as therapists to make the service more meaningful and meet the complex needs of the service users.

### **7.3.6: Mental Health Crisis Teams**

The team at the community mental health service is available to provide support on weekdays from 9 am to 5 pm. By offering assistance in familiar surroundings, individuals are more likely to seek help, which can foster a sense of belonging and reduce the isolation often associated with mental health challenges. However, it's important to recognise the limitations of weekday-operated services. These services may not be able to accommodate crises that arise outside of these hours, and individuals with severe or acute mental health conditions may require round-the-clock care. To address these concerns, a crisis resolution care service should be established to work alongside the community mental health team. The crisis team will be responsible for dealing with crises in the community between 5 pm and 9 am, as well as on weekends.

The implementation of government-led community mental health care services that operate round-the-clock care can be a highly valuable initiative for mental health support systems. These services provide accessible, routine-based care within communities, addressing the needs of individuals who require mental health support. These services contribute greatly to early intervention, ongoing support, and the reduction of stigma surrounding mental health, which is a crucial aspect of comprehensive mental health care.

The availability of such services ensures that individuals can access the care they need at the earliest possible stage, preventing the escalation of mental health issues. By providing routine-based care, these services offer a structured approach to mental health care that individuals can rely on. Additionally, these services contribute significantly to the reduction of stigma surrounding mental health, which is a key factor in encouraging individuals to seek help without fear of judgement.

While these services cater to a wide range of individuals, it is important to note that the provision of a comprehensive mental health system must ensure a continuum of care that addresses the varying needs of individuals. This includes those that go beyond weekday schedules, as mental health issues can arise at any time. Therefore, it is essential to have a range of services available that can cater to individuals' diverse mental health needs, ensuring access to care when it is needed the most.

### **7.3.7: Review of Education and Training for nurses**

The mental health nurses are required to provide support expeditiously. They are required to keep clear and accurate records. This study highlights that the nurses are mainly concerned

with carrying out their daily functions. However, previous evidence (van de Ven et al., 2017, Peddle et al., 2020) indicates that nurses do not spend time writing about what they do to help identify any learning gaps. This indicates that nurses must be encouraged to allocate time for writing about what they do to help identify any learning gaps. This can become an important area of learning that requires attention. Ongoing training is essential for mental health nurses to enhance their expertise and capabilities in providing care. Mental health services are advised to offer complimentary training opportunities for practicing nurses. It has come to light that community mental health nurses in Ghana may lack the skills for creating nursing care plans, which is a vital aspect that needs to be taught and applied without delay. Conducting training sessions on care planning for nurses will enable them to assess the progress of service users, resulting in better quality care. As such, it is critical for the service to prioritise risk assessment as a fundamental course for nurses.

Nurses need to update their knowledge and skills regularly and continuing professional development (CPD) programmes must help to facilitate updating of skills (Mlambo et al., 2021). Continuing professional development is both formal and informal training for nurses to update their knowledge, skills and competences within practice environment (Wray & Aleo, 2021). CPD programmes are pivotal to nurses' lifelong learning and are a fundamental aspect for keeping nurses' knowledge and skills up to date and can be mandatory or voluntary (Pool et al, 2016; Ross et al., 2013). Nurses take part in CPD because it is a requirement and breaching it has ramifications for the individual's profession (Ross et al., 2013; James and French, 2011). CPD for nurses is mandatory in the United Kingdom and Australia because the regulator for nursing and midwifery has made it a requirement for remaining on the professional register to practise (Royal College of Nursing, 2019; James and French, 2011).

For the nurses in Ghana to continue to remain on the Ghana Nurses and Midwifery Council (GNMC) register and to practise, mandatory CPD is required. It is therefore important for the GNMC to propose to the government the importance of CPD for nurses and lobby for funding this course. The delivery of courses for nurses needs funding. The courses may lead to enhanced certification and also to career progression. The healthcare employer and the government can deliver the courses that meet the skill needs of nurses across the country. Where CPD becomes optional, it can minimise the drive to enforce it and audit it for improvement. It is therefore necessary to make it a priority and connected to GNMC revalidation requirements.

## **7.4: Contribution to Knowledge**

This study is significant in establishing contemporary facts, in relation to exploring the support for service users and their caregivers in Ghana, thus making conceptual and methodological contributions to the field of study that may also be transferable to other similar contexts in wider mental and general health provision.

### **7.4.1: Conceptual framework contribution**

The study's significance lies in its use of the EMHP framework together with the ladder of citizen participation in exploring the support given to service users diagnosed with schizophrenia and their caregivers in Ghana. This represents the first time these conceptual frameworks have been used in such a study in the Ghanaian context to the best of my knowledge. The community intervention model (McElroy et al., 1988) has mostly been used in studies in the developed world. Therefore, the community intervention model was adapted to explore the support service users and caregivers receive in Ghana. From the model, actions are deemed useful when they meet the needs of service users and caregivers who receive healthcare services. The interaction between nurses (and other clinicians) and service users/caregivers is intended to address mental and related wellbeing problems, and the significance of people's actions are expressed within a social context. As such, mental health services are established to offer services that support society's overall wellbeing. The mental health services' vision statement must align with society's requirements to ensure its continued relevance. In this context, the community mental health services are responsible for catering to the needs of service users, enabling them to better function in society. The ladder of citizen participation framework (Arnstein, 1969) was also adapted to explore the support given to service users diagnosed with schizophrenia and their caregivers in Ghana. This framework highlights the powerlessness of service users and caregivers in getting the support they need as they tend to rest at the bottom half of the ladder in practice.

### **7.4.2: Methodological contribution**

A key contribution is that this is also the first time the Interpretive Phenomenological Analysis (IPA) has been used in exploring the support given to service users diagnosed with schizophrenia and their caregivers in Ghana. Even though the findings of the study are not intended to be generalised beyond the scope of the detailed exploration of the accounts of the 10 service users, 21 caregivers, and six mental health nurses. However, by utilising the IPA

method, the study sought to go beyond a simple description and categorisation of salient themes (Rizq & Target 2008). The findings suggest the possibility of a new conceptual and integrative model as a philosophical approach to how we perceive caregiving and support, which is consistent with and rooted in the subjective phenomenology of the participants' experiences.

It is possible to support service users who have been discharged to their homes, to live well in the community, by adequately providing for their health needs. However, it can be difficult to access health facilities where resources are scarce, including medication and resource centres, which often leaves families with little support. Choguill (1999) argues that what is suitable for one person should be good for the public, particularly in developing countries. It is crucial to find ways of supporting and improving mental healthcare services for service users diagnosed with schizophrenia and their caregivers in Ghana.

### **7.5: Suggestions for further research**

Including psychiatrists in the study could have enhanced its findings by providing additional evidence to support the interview data and could have augmented its conclusions and reinforced the data gathered through interviews. Additionally, conducting a replication of the study with psychiatrists in the same geographic area would be advantageous for further analysis.

To enhance the scope of this research, future studies may wish to explore the encounters of service beneficiaries and caregivers in alternative geographical areas of the nation. Conducting comparative analysis of the experiences of both groups across various administrative regions would offer a more exhaustive and nuanced understanding.

Another promising avenue for further investigation is to delve into the requirements of caregivers and develop a specialised service aimed at enhancing their experiences and mitigating the challenges associated with caregiving.

### **7.6: Conclusion**

The move of mental health services in Ghana; from the hospital-based to the community-based services has highlighted the need to examine the support given to people diagnosed with schizophrenia and their caregivers living in Ghana as well as for the community mental

health service users and their family caregivers. The study indicated that various issues were associated with the support provided for service users and their family caregivers.

This study established that the concept of what constitutes support within the Ghanaian context and specifically in the study enclave covered the provision of general, physical, and psychological assistance. General support therefore encompassed diverse forms of assistance and care without being tied to a specific type or method. This is important, because such support was valued even though it did not fall within physical and psychological support, such as willingly performing an act that benefits the person receiving it without being compelled to accept it. Physical support was seen as a practical and tangible aid to others in the form of items such as money, food, assistance with transportation and consumables. Thus, physical support helps caregivers to manage the burden of providing care and also to provide for the basic needs of service users. Psychological support on the other hand covered emotional, spiritual and counselling support - all aimed at alleviating mental distress alongside the provision/and availability of psychotropic medications for service users and reassuring caregivers. The nature of professional support for community mental health service users, crossed over with other aspects of support. This professional support was seen as including care review for service users, assessing service user needs, health promotion for service users, access to medication and treatment, and counselling. In examining the experiences of nurses providing care in the community mental health services and the challenges they experience, these again were intertwined. The study demonstrated that the provision of community mental healthcare services was plagued by numerous challenges, such as the lack of free psychotropic medication for service users, irregular staff training, stigmatising attitude towards mental disorder, and transportation problems for mental health nurses. These challenges therefore need to be addressed if support is to be improved for service users and caregivers. It therefore follows that the study highlighted that services provided to caregivers were either absent or woefully inadequate, for example, in terms of addressing fatigue in caregiving and respite care, thereby undermining the provision of adequate support for the wellbeing of service users and their caregivers.

It is in the light of the above that several recommendations have been advanced, given that the study highlights a number of gaps that need addressing in policy and practice. Consequently, this study proposes that the government establishes robust policy planning and implementation by undertaking policy reform of mental health services in relation to caregivers assessment; the provision of free psychotropic medication; highlighting the value of caregiver group support; provision of transportation for nurses, resource centres; putting in place proactive mental health crisis teams; and reviewing education and training for nurses. These

reforms will go a long way to improve the support available to service users diagnosed with schizophrenia and their caregivers.

Essentially, adequately supporting service users diagnosed with schizophrenia and their caregivers in community mental health settings is critical given the enormous burden of caring for such service users due to the chronicity and significant ill health it subjects service users to. The indirect yet severe negative impact of schizophrenia and other mental illnesses on caregivers, notwithstanding best efforts of community mental health nurses, such efforts still fall short in terms of support. Therefore, without proper resourcing or support of community mental health services, service users diagnosed with schizophrenia and their caregivers will still not receive the desired outcomes.

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# APPENDICES

## Appendix 1- Middlesex University's Health and Education Ethics Committee Conditional Approval Letter



School of Health & Education  
The Burroughs  
Hendon  
London NW4 4BT

Main Switchboard: 020 8411 5000

18<sup>th</sup> October 2016

**HEESC APPLICATION NUMBER: MH51 Godfred Asamoah**

Dear Godfred

**Re your application titled** "Supporting people with diagnosis of schizophrenia living in the community and their families, Ghanaian perspective"

The Health and Education Ethics Committee has reviewed your application and has approved subject to the following amendments being addressed. An application that is approved subject to amendment must be returned to Leeann Bradley [HEethicsSubC@mdx.ac.uk](mailto:HEethicsSubC@mdx.ac.uk) within 20 working days for consideration by Chairs action or normal review.

#### **Ethics Form**

- The consent issues are addressed well and comprehensively in the proposal though the withdrawal aspect is not articulated reassuringly enough for the patient participant to know that the service/care will not be affected by such a decision. Clarify further if and how participants can withdraw from the project. (Any consequences?)
- Section 9 - Signatures needed

#### **PIS**

- Use University template <http://ethics.middlesex.wikispaces.net/Health+Studies>

#### **Other**

- remove the NSEC forms from your documents as you are not going to use them (As you aware you are applying to Health Ethics Committee)

You must advise the committee if you are unable to respond to the conditions within 20 working days. Please cite the application number in all correspondence.

You must not start your research until you have received an ethics approval letter.

## Appendix 2 - Middlesex University's Health and Education Ethics Committee Approval



School of Health & Education  
The Burroughs  
Hendon  
London NW4 4BT

Main Switchboard: 020 8411 5000

Friday 26th May 2017

**HEESC APPLICATION NUMBER: MH51 - GODFRED ASAMOAH**

Dear Godfred,

**Re your application titled "Supporting People with Diagnosis of Schizophrenia Living in the Community and Their Families, A Ghanaian Perspective"**

Thank you for submitting your revised application. I can confirm that your application has been given approval from the date of this letter. This approval is valid 30<sup>th</sup> September 2018. If you require an extension to this end date please complete Form E which can be found at <http://ethics.middlesex.wikispaces.net/Health+Studies>

Please ensure that you contact the ethics committee via [HEethicsSubC@mdx.ac.uk](mailto:HEethicsSubC@mdx.ac.uk) if there are any changes to the study to consider possible implications for ethics approval. Please quote the application number in any correspondence.

The committee would be pleased to receive a copy of the summary of your research study when completed.

Good luck with your research.

Yours sincerely

A handwritten signature in black ink that reads "Gordon".

Dr Gordon Weller  
Chair of Health and Social Care Ethics Sub-Committee

## Appendix 3 - Middlesex University's Health and Education Ethics Committee Amendment Approval (Additional participant group)



6<sup>th</sup> April 2018

Mr Godfred Asemoah

Re: Amendment request to ethics application No: MH51

Dear Godfred,

An amendment to the above application in respect of inclusion of an additional participant group has been approved. Please advise the committee of any further changes prior to undertaking research.

Kind Regards

Avni Shah

Administrator for Health and Social Care Ethics Sub-Committee.



## Appendix 4- Director of Studies, Middlesex university's introductory letter to Ghana Health Service Ethics Committee

**Middlesex University (London)**

**School of Health and Education  
Dept. of Mental Health, Social Work & Integrative  
Medicine  
The Burroughs, Hendon.  
London. NW4 4BT.  
[www.mdx.ac.uk](http://www.mdx.ac.uk)  
Main Switchboard: 00442084115000  
19<sup>th</sup> July 2016.**

**The Director  
Ghana Mental Health Authority  
Accra Psychiatric Hospital  
Accra. Ghana**

Dear Director,

This letter is to seek your approval for a study entitled 'Supporting People with Diagnosis of Schizophrenia Living in the Community and Their Families, The Ghanaian Perspective' to be conducted. This study is to be conducted by Godfred Asamoah, a doctoral research student at the School of Health and Education, Middlesex University in London, United Kingdom.

The proposed study aims at exploring the support for the people diagnosed with schizophrenia and their families, with emphasis on the community mental health service. The patients and their families will be interviewed (in one-to-one interviews) to explore their experiences around support. A sample of Mental Health professionals will also be interviewed in one-to-one interviews to explore service level input.

The participation in this study will cause no harm or risk to the participants as individuals or collectively. All information that will be collected from the participants through interviews will be kept confidential. The data collected will only be accessed by the researcher. The data will be anonymised by using pseudonyms or a reference number to protect the participants and their details right from data collection stage, data analysis and findings reporting stage.

Please, find attached to this letter the following documents for your consideration: a brief proposal of the study, a participant information sheet, and a consent form.

The findings of this study will be used for academic purpose, PhD dissertation. The findings will be published in a peer reviewed journals. The study may offer a lead to further research, help guide future decisions on mental healthcare reviews, and policy formulation in Ghana. Please, in case there are any ethical concerns you may contact the researcher via email [gfed@hotmail.co.uk](mailto:gfed@hotmail.co.uk) or 00447534909636. We would appreciate if you could kindly approve this study to be conducted in Ghana.

Thank you.  
Yours sincerely,

Professor Peter Ryan ([p.ryan@mdx.ac.uk](mailto:p.ryan@mdx.ac.uk))  
Director of Studies.

Appendix 5- Local supervisor's letter of support to the letter to Ghana Health Service Ethics Committee



**UNIVERSITY OF GHANA**  
**DEPARTMENT OF PSYCHOLOGY**  
**SCHOOL OF SOCIAL SCIENCES**

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Ref. No.....

19<sup>th</sup> September, 2016

The Chairperson  
Ghana Health Service Ethics Review Committee  
Research and Development  
Adabraka Polyclinic  
Accra.

Dear Chair,

I write to inform you that I have consented to be the local academic supervisor for Godfred Asamoah, a PhD student from Middlesex University, London Campus in United Kingdom. I will, therefore, be supervising him during his data collection whilst in Ghana.

Please, find attached a copy of my curriculum vitae as requested.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Samuel Atindanbila'.

Dr Samuel Atindanbila  
Senior Lecturer/ Clinical Psychologist  
satindanbila@ug.edu.gh  
+233-277532705

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COLLEGE OF HUMANITIES

P. O. Box 14, Legon, Accra-ghana

• Telephone: +233 (0) 289 550 463

• Email: Psychology@ug.edu.gh

• Website: www.ug.edu.gh

Appendix 6- Ethics approval by the Ghana Health Service Ethics Committee

GHANA HEALTH SERVICE ETHICS REVIEW COMMITTEE

*In case of reply the number and date of this letter should be quoted.*



Research & Development Division  
Ghana Health Service  
P. O. Box MB 190  
Accra  
Tel: +233-0302-681109  
Fax: +233-0302-685121  
Email: [ghserc@gmail.com](mailto:ghserc@gmail.com)  
29<sup>th</sup> June, 2017

By Ref: GHSRDD/ERD/ADMIN/APP/17/513  
Your Ref. No.

Godfred Asamoah  
School of Health and Education  
Middlesex University  
London, United Kingdom

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

GHS-ERC Number	GHS-ERC: 09/09/2016
Project Title	Supporting People with a Diagnosis of Schizophrenia Living in Community and their Families. A Ghanaian Perspective
Approval Date	25 <sup>th</sup> June, 2017
Expiry Date	19 <sup>th</sup> June, 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 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 DANNERMAN  
(GHS-ERC CHAIRPERSON)

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

Appendix 7- Ethics amendment Approval by the Ghana Health Service Ethics Committee

GHANA HEALTH SERVICE ETHICS REVIEW COMMITTEE

*In case of reply the number and date of this Letter should be quoted*



Research & Development Division  
Ghana Health Service  
P. O. Box MB 190  
Accra

Tel: +233-0302-681109  
Fax + 233-0302-685424  
Email: ghserc@gmail.com  
10<sup>th</sup> May, 2018

My Ref. ghs/rd/erd/Admin/APP/17/Amend  
Your Ref. No.

Godfred Asamoah  
School of Health and Education  
Middlesex University  
London, United Kingdom

**RE: REQUEST FOR PROTOCOL AMENDMENT TO INTERVIEW HEALTH STAFF PARTICIPANTS BY TELEPHONE**

Reference is made to your letter dated 8<sup>th</sup> May, 2018 on above subject matter.

The Ghana Health Service Ethics Review Committee has reviewed and given approval for implementation of the amendment

GHS-ERC Number	GHS-ERC: 09/09/2016
Project Title	Supporting People with a Diagnosis Schizophrenia Living in Community and their Families, A Ghanaian Perspective
Effective Date of Amendment	11 <sup>th</sup> May, 2018
GHS-ERC Decision	Amendment Approved

The approval covers the following only:

- To interview health staff participants by telephone
- Consenting to Participate: Use of e-mail system to ensure that health staff participants sign consent forms before telephone interview.

The following applies:

- 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 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.

Please note that this approval does not cover transfer of material to any institution.

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

SIGNED   
PROFESSOR MOSES AIKINS  
(GHS-ERC VICE CHAIRMAN)

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



## **Version Number...VII**

### **PARTICIPANT INFORMATION SHEET (PIS) FOR STAFF INTERVIEW**

**1. TITLE OF RESEARCH/STUDY: SUPPORTING PEOPLE WITH A DIAGNOSIS OF SCHIZOPHRENIA LIVING IN THE COMMUNITY AND THEIR FAMILIES: THE GHANAIAN PERSPECTIVE**

**2. Invitation paragraph**

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear to you or if you would like more information. Take time to decide whether or not you wish to take part in the research.

Thank you for reading this.

**3. What is the purpose of the study?**

The focus of community mental healthcare in Ghana is to deliver care to patients in their own homes and community, thereby promoting independence and social integration. However, the ethos of the community mental healthcare has had its problems in developing countries, Ghana being one of them. Despite the obvious financial and cultural problems, mental health organisations try to find ways to engage their service users. Mental health services also support caregivers of people with mental health problems, and help to reduce distress. The main focus of this study is to evaluate the services the community mental health service offers.

To be able to achieve the aim of this study, you will be asked to participate in a telephone interview with the researcher. The interview will involve questions about the services you provide to your patients. It will include what works well and the challenges you face in the work you do. This will take about 30-45mins.

#### **4. Why have I been chosen?**

You will recall that the researcher visited your team at the time when he was recruiting patients into the study. After further review of the literature and suggestions from the academic supervisors, staff in your team are now being interviewed as part of the study. We think staff contribution to this study will enrich the data being collected and also add different perspectives to the research. We are inviting you as a community mental health clinical staff (nurse/doctor) in your team. We would like to hear about your experiences to improve our understanding of the service you provide. Your experience is important because it may help to shape and improve the current Mental Health Services.

If you are willing to participate in the study, the researcher will ask you to complete a consent form online and return it to him.

We are recruiting 10 members of staff for the study.

#### **5. Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be sent this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

A decision to withdraw at any time, or a decision not to take part, will not impact on your work in any way or shape.

#### **6. What will happen to me if I take part?**

The nature of this study is a semi-structured interview method. If you agree to take part in the study, the researcher (Godfred Asamoah) will contact you by telephone to discuss a bit more about the study and if you are still willing to participate in the study you will sign a consent form online through Survey Monkey questionnaire.

After receiving your written consent form, you and the researcher will have a telephone interview. At this stage of the study, we would like to

interview staff in the community mental health team so that we can learn about their experiences of supporting service users and their families. This stage of the study will involve you answering some questions about the support you offer to service users and their families. With your consent the interview will be audio recorded.

Please note that in order to ensure quality assurance and equity this project may be selected for audit by a designated member of the Research Ethics Committee. This means that the designated member can request to see signed consent forms. If this is the case, your signed consent form will only be accessed by the designated auditor or member of the audit team.

#### **7. What do I have to do?**

If you decide to take part you will be involved in a telephone semi-structured interview where you will be invited to discuss your experiences with the researcher. This interview will take between 60-90 minutes. You will be required to answer questions about your experiences with the Community Mental Health Service.

You may be contacted again if the researcher thinks that some of the points you raised in your semi-structured interview need clarification.

OR

Where the previous interview session was not completed because of unforeseen circumstances such as a poor telephone connection (prolonged noise/ breaks during the telephone conversations) the interview session will be rescheduled to complete it as soon as possible.

You will be contacted again to validate your responses to the first interview.

#### **8. What are the possible disadvantages and risks of taking part?**

You may be inconvenienced by the time required to consider and participate in a telephone interview with the researcher. There is a small risk that you may become upset when talking about your experiences. If you become upset the researcher who is a trained mental health nurse will offer a break from the interview or consider the option of ending the interview session and can reconvene to continue from where the interview last ended. In the extreme case of being distressed by sharing your experiences, the interview may be terminated by either the researcher or you. If the researcher terminates the interview, he will give you a reason. However, should you decide to withdraw from the study, you can do so at any point without needing to give any reason. In case you want to withdraw from the study, please feel free to tell the researcher. The researcher may ask you to sign a form to show that you have withdrawn from the study.

Please, be aware that if you decide to withdraw from the interview, it will not affect your privileges outside this study. Also, be aware that if you decide to withdraw from the study, you will not be reprimanded in any way.

Please, note that even after the interview, you can voluntarily withdraw from the study, and have up to the time of publication of the study to do so by informing the researcher of your decision to withdraw from the study.

## **9. What are the possible benefits of taking part?**

We hope that participating in the study will help you. However, this cannot be guaranteed. The information we get from this study may help us to handle future participants with a diagnosis of schizophrenia and their families better.

Findings from this study will be used for academic research purposes.

The information gained from the study may help the Mental Health Authority work out the best way to work with service users with a diagnosis of schizophrenia and their families with a view to finding out more about incorporating social support into healthcare.

#### **10. Will my taking part in this study be kept confidential?**

All information that is collected about you during the course of the research will be kept strictly confidential. Any information about you which is used in the research will have your name and address removed so that you cannot be recognised from it.

Please, be aware that all data will be stored, analysed and reported in compliance with the Ghana Data Protection Act (2012). However, if you disclose any unprofessional or risky clinical practice, then the researcher will have to discuss this with you and your manager or any relevant agency. The researcher by his professional standard:

NMC code [www.nmc-uk.org/Nurses-and-midwives/The-code/](http://www.nmc-uk.org/Nurses-and-midwives/The-code/) states that, as nurses and midwives 'you must disclose information if you believe someone may be at risk of harm, in line with the law of the country in which you are practising'.

#### **11. What will happen to the results of the research study?**

The transcript will be added to other transcripts generated from the other interviews and used for data analysis.

The researcher will supply you with the summary of the research findings through the Manager at the Community Mental Health Team's office.

The researcher will write reports and make presentations as part of his academic work. The reports will allow the results to be shared as widely as possible. These publications and presentations will not identify any single individual participant or the Community Mental Health team by name.

#### **12. Who has reviewed the study?**

This study has been reviewed by the Health and Social Care Ethics Subcommittee (Middlesex University, School of Health and Education).

#### **13. Contact for further information**

1. Godfred Asamoah (Researcher)  
Middlesex University (London Campus)  
School of Health and Education  
The Burroughs, Hendon.  
NW4 4BT.  
Email: [GA490@live.mdx.ac.uk](mailto:GA490@live.mdx.ac.uk)

**PhD Supervisors:**

2. Dr Gordon Weeler (Director of Study)  
Middlesex University (London Campus)  
School of Health and Education  
The Burroughs, Hendon.  
NW4 4BT.  
Telephone: 00442084114908  
Email: [g.weller@mdx.ac.uk](mailto:g.weller@mdx.ac.uk)
3. Dr Lisa Clarke  
Dr Lisa Louise Clarke, Fellow HEA  
Faculty of Professional and Social Sciences  
School of Law  
Department of Law and Politics  
Middlesex University  
The Burroughs, Hendon  
NW4 4BT.  
Email: [L.Clarke@mdx.ac.uk](mailto:L.Clarke@mdx.ac.uk)
4. Dr Michael Kelly (Supervisor)  
Middlesex University (London Campus)  
School of Health and Education  
The Burroughs, Hendon.  
NW4 4BT.  
Telephone: 00442084114908  
Email: [M.A.Kelly@mdx.ac.uk](mailto:M.A.Kelly@mdx.ac.uk)

Thank you for reading this information sheet and for taking part in this study.

Please, a copy of the information sheet is for you to keep.

**Date:** .....2018

**Version No:** VII



## **Version Number...VI**

### **Participant information sheet for service users and caregivers**

#### **1. Study title: SUPPORTING PEOPLE WITH DIAGNOSIS OF SCHIZOPHRENIA LIVING IN THE COMMUNITY AND THEIR FAMILIES, A GHANAIAN PERSPECTIVE.**

#### **2. Invitation paragraph**

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

#### **3. What is the purpose of the study?**

Currently, there is emphasis on community mental healthcare in Ghana as a way of ensuring services delivered reach majority of those who need them. This approach provides a lot of advantages for the patients to live optimally in their own homes. However, patients and their families may have some difficulties in relation to providing care. It is important for organisations to find ways of doing things with those who use their services. This has raised the need to explore the views of patients and their families around the support they receive from their local mental healthcare service. The main focus is to evaluate the service you or your relative get from the community mental health service.

To be able to achieve the aim of this study, you will be asked some questions by the research student in a one-to-one and face-to-face interview. The interviews may take between 45-90mins.

#### **4. Why have I been chosen?**

We are inviting people diagnosed with schizophrenia and their families from the Community Mental Health Service to take part in this study. You have been invited to participate because your experiences with the

Mental Health Services are very important in shaping the current mental health services for a better future of the service.

You have been chosen to participate in this study because you are (i) 18 years or older, (ii) male or female, (iii) you have a link with the Community Mental Health Service and (iv) you can talk to our research student about the service. If you are willing to participate in the study, kindly complete the attached consent form and return it to the research student.

We are recruiting between 10-15 service users and 10-15 family members for the study.

#### **5. Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

#### **6. What will happen to me if I take part?**

The nature of this study is a survey method.

If you agree to take part in the study, the researcher (Godfred Asamoah) will meet up with you and discuss a bit more about the study and if you are still willing to participate in the study you will sign a consent form.

This stage will involve you answering some questions about your experiences with the Mental Health Service and support you get. With your consent the interview will be audio recorded. We will then transfer the recording into writing and will ask you to read it to ensure it is the correct information you provided. Once you are happy with this, the audio recording will be deleted. The write-up will then be used for analysis.

The researcher will visit you at your home or agree on a convenient and a safe place for meeting for interviewing.

Please note that in order to ensure quality assurance and equity this project may be selected for audit by a designated member of the

Research Ethics Committee. This means that the designated member can request to see signed consent forms. If this is the case, your signed consent form will only be accessed by the designated auditor or member of the audit team.

#### **7. What do I have to do?**

This study is over two months and consists of approximately two to three visits. During the first visit you will be informed and invited to take part in this study and it will take about 30-40 minutes. The second visit will be about 20 minutes to collect the consent form. The third visit will be longer than the previous visits.

During the third visit you will be required to answer questions about your experiences with the Community Mental Health Service. You will be involved in one-to-one and face-to-face semi-structured interviews where you will tell the research student about your experiences. This interview will take between 45-90 minutes.

The research will take about two months. You will only be contacted about 2-3 times.

#### **8. What are the possible disadvantages and risks of taking part?**

You may be inconvenienced by the time required to consider and participate in a face-to-face and one-to-one interview with the researcher. There is a small risk that you may become upset when talking about your experiences. If you become upset the researcher who is a trained mental health nurse will offer a break from the interview or the option of ending the interview session and can reconvene to continue from where the interview last ended. In the extreme case of being distressed by sharing your experiences the interview may be terminated by either the researcher or you. If the researcher terminates the interview, he will give you a reason.

However, where you decide to withdraw from the study, you can do so at any point without needing to give any reason. In case you want to withdraw from the study, you tell the researcher. The researcher may

ask you to sign a form to show that you have withdrawn from the study. Please, be aware that if you decide to withdraw from the interview, it will not affect your care in any way. You will continue to receive the care as planned. Also, be aware that if you decide to withdraw from the study, no one will penalise you for doing so.

**9. What are the possible benefits of taking part?**

We hope that participating in the study will help you. However, this cannot be guaranteed. The information we get from this study may help us to treat future participants with (name of condition) better.':

Your views about the kind of support you get will help us to have a better understanding about the service you currently receive.

Findings from this study will be used to achieve academic research purpose.

The information gained from the study may help the Mental Health Authority work out the best way to work with service users with a diagnosis of schizophrenia and their families with the view to finding out more about incorporating social support into healthcare.

**10. Will my taking part in this study be kept confidential?**

The Ghana Data Protection Act (2012) will apply to all data gathered in the interviews. Therefore, any information collected from you will be kept confidential. However, if you disclose any risky activity, then the researcher will have to discuss this with you and your care team.

The researcher, as a nurse (by his professional standards), must disclose information if he believes someone may be at risk of harm, in line with the Nurses and Midwifery Council (UK) code. You may read the details of the code from the link provided here: NMC code [www.nmc-uk.org/Nurses-and-midwives/The-code/](http://www.nmc-uk.org/Nurses-and-midwives/The-code/) states that as nurses and midwives 'you must disclose information if you believe someone may be at risk of harm, in line with the law of the country in which you are practicing'.

An audio recording device will be used to record the interview. This recording will be transferred into writing (transcription). The researcher will show you the written form of your interview (transcript) for approval. The information collected from you will be stored in locked cabinets and password-locked computer. The collected data will only be accessed by the researcher. Anonymity of participants will be ensured by assigning a unique study identifier (as opposed to your name) and this will be stated at the start of each interview. Any disclosure of information by you, which would potentially reveal your identity, will be removed at the report writing stage. Once you confirm you are happy with the transcripts, the recording will be erased completely in accordance with the Middlesex University's Ethics Policy.

**11. What will happen to the results of the research study?**

The findings of this study will be published as part of a postgraduate dissertation. The results of this are likely to be published in later in 2019. You may contact the researcher for the results from June to December 2019. You will not be identified in any report/publication.

**14. Who has reviewed the study?**

This study has been reviewed by the Health and Social Care Ethics Subcommittee (Middlesex University, School of Health and Education) and the Ghana Health Service Ethics Review Committee.

**15. Contact for further information**

1. Godfred Asamoah (Researcher)  
Email: GA490@live.mdx.ac.uk
2. Prof Peter Ryan (Director of Study)  
School of Health and Education  
Middlesex University (London Campus)  
Telephone: 00442084114908  
Email: P.Ryan@mdx.ac.uk

5

3. Dr Michael Kelly (Supervisor)  
School of Health and Education  
Middlesex University (London Campus)  
Telephone: 00442084114908  
Email: M.A.Kelly@mdx.ac.uk

Thank you for reading this information sheet and for taking part in this study.

**Date:** .....

You will be given a given a copy of the information sheet and a signed consent form to keep.



**Version Number...VI**

Participant Identification Number:

**CONSENT FORM**

**Title of Project: SUPPORTING PEOPLE WITH DIAGNOSIS OF SCHIZOPHRENIA LIVING IN THE COMMUNITY AND THEIR FAMILIES, A GHANAIAN PERSPECTIVE.**

**Name of Researcher: GODFRED ASAMOAH**

Please initial box

- |   |   |
|---|---|
| 1. I confirm that I have read and understand the information sheet dated .....for the above study and have had the opportunity to ask questions.  | 1 |
| 2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.   | 2 |
| 3. I agree that this form that bears my name and signature may be seen by a designated auditor.   | 3 |
| 4. I agree that my non-identifiable research data may be stored in National Archives and be used anonymously by others for future research. I am assured that the confidentiality of my data will be upheld through the removal of any personal identifiers.  | 4 |
| 5. I understand that sections of any of my medical notes may be looked at by responsible individuals from Middlesex University, United Kingdom or from regulatory authorities where it is relevant to my taking part in research. I give permission for these individuals to have access to my records. | 5 |
| 6. I understand that my interview may be taped and subsequently transcribed.  | 6 |
| 7. I agree to take part in the above study.   | 7 |
| 8. I give consent to my carer to be approached (where applicable)   | 8 |

Name of participant	Date	Signature
---------------------	------	-----------

Name of person taking consent (if different from researcher)	Date	Signature
---	------	-----------

Researcher	Date	Signature
------------	------	-----------

1 copy for participant; 1 copy for researcher;

Appendix 11 - Consent form for staff participants

MH51

**Version Number VII...**  
Participant Identification Number:



**CONSENT FORM**

**Title of Project: Supporting People With a Diagnosis of Schizophrenia Living in the Community and Their Caregivers: The Ghanaian Perspective.**

**Name of Researcher: Godfred Asamoah**

Please initial box

1. I confirm that I have read and understand the information sheet dated .....for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, within the limitations cited in the information sheet, without giving any reason.
3. I agree that this form that bears my name and signature may be seen by a designated auditor.
4. I understand that my interview may be taped and subsequently transcribed.
5. I agree to take part in the above study.

\_\_\_\_\_  
Name of participant                      Date                      Signature

\_\_\_\_\_  
Researcher                      Date                      Signature

1 copy for participant; 1 copy for researcher;

Appendix 12- Interview guide for service users  
MH51

**VERSION 4**

**Participant Code:**

**INTERVIEW GUIDE: SERVICE USER**

**Research Title:** Supporting People with Diagnosis of Schizophrenia Living in the Community and Their Families: The Ghanaian Perspective.

This interview guide is designed to help obtain information that will be used in assessing the support that people in Ghana diagnosed with schizophrenia and their carers receive. This is a Postgraduate (PhD) research project supported by the Department of Mental Health, University of Middlesex (England). Kindly supply the required information in the spaces provided below. You are assured that information you provide will be treated with strictest confidentiality.

Please, this paper has two sections (Section A and Section B). The researcher will assist you to complete Section A when required. You will discuss section B during your meeting with the researcher.

**Date:** [This section will be left blank for participant to complete]

**A. Please, state your answers in spaces provided**

- i. Age.....**
- ii. Gender.....**
- iii. Educational background.....**
- iv. Employment status.....**
- v. Annual Income.....**

**Signature.....Date.....**

**B This section is for you to talk about in our meeting. Your comments will be audio recorded as explained to you in our previous conversation.**

- What does support mean to you?
- Tell me your experiences of caregiving

Prompts:

- Any support you receive from family and friends
  - E.g. meal times, financial help etc.
- 
- What do you think are the day-to-day challenges you experience?
- 
- Kindly tell me any support you get from the Mental Health Service
- Prompts:
- Medication
  - Information on health promotion
  - Information on how to detect that your mental condition is getting worse
  - How often do the mental health staff see you?
  - How long do they see you when they visit?
  - What do they do when they visit?
  - What other support do you get that you have not mentioned? E.g. support from your religious group, or any other group?
  - How do you seek help from the mental health service?
- 
- How do you judge the level of support you receive from the mental health service?
  - What other things do you need to help you cope with the problems?
  - In your view, what can be done to improve the support you receive?

Appendix 13- Interview guide for caregivers

**INTERVIEW GUIDE FOR CAREGIVERS**

**Title: Supporting People with a Diagnosis of Schizophrenia Living in the Community and Their Families, A Ghanaian Perspective**

**Date: 15/01/2017**

- What do you think are the day-to-day challenges you experience?
- What do you think 'social support' means to you?
- What support do you get from your family?
  - Prompts: physical needs, mealtimes
- What support do you, as a patient, get from the mental health team?
- What support as a caregiver do you get from the mental health team?
- How do you rate the level of support received from the mental health team?
- What other things do you need to help you cope with the problems?
- How do you feel about the activities the mental health staff do with you?

## INTERVIEW GUIDE FOR HEALTHCARE PROFESSIONALS

1.

People who are diagnosed with mental health issues and their caregivers need to be supported. You have been interacting with people with mental health problems and are familiar with their health needs. From your day-to-day interaction with people diagnosed with mental health issues that you support, could you please:

- Tell me about your understanding of 'support' in relation to your work.
- Tell me about the types of support you offer the service users and their caregivers

2.

People with mental health problems and their relatives need help from people around them.

Please, tell me about the kind of support you know family caregivers receive from friends and other families.

Please, explain the kind of support that has been beneficial to the:

- (i) service users
- (ii) caregivers

What support has been least beneficial to the:

- (i) service users?
- (ii) caregivers?

Please, tell me about the differences in the support you and the family offer. How adequate is that support?

3.

\* Tell me about how you (CMHS) support service users living in the community.

\* Tell me about how you support families to cope with the demands of caring for their sick relatives.

Probe: Any information given to help them?

\*Explain caregiver plans your service (CMHS) has designed for the families

Probe: What assessment have you done on caregivers?

\*Are there any policies that guide your caregiver assessment? If "Yes", could you please state them?

4.

a. Please tell me about the challenges your service (CMHS) faces in providing support for community service users and their families.

Probe: What are the challenges?

b. How can the identified challenges be overcome?

Probe: What solutions do you suggest?

Do you want to make any other comments?

## Appendix 15: Sample of conversation with participants

“Hello. “My name is Godfred Asamoah. I am a student from Middlesex University in London, UK. I am researching into support service users and their caregivers receive. I am a mental health nurse in the United Kingdom but I am speaking with you as a graduate research student. I have heard so much about mental health service in Ghana. Service users and/or their caregivers are to buy their medication. In my study at the University, I am learning about support for people who experience schizophrenia and their caregivers. I have come to learn from you. I will share your experiences with me. I am here for the next three months. I will return to the United Kingdom to continue my studies. If you are interested to be part of my study, I can give you the information sheet for you to study. You can call me if you want to talk about your experiences around schizophrenia. You can ask me questions about this study. This my number written on the Participant Information Sheet. You can sign the consent form if you willingly agree to speak with me again and tape recorded. Thank you so much for listening to me this morning.”

## Appendix 16: Stages of back-translation of Semi-structured Guide

### Stages of back-translation of semi-structured guide (SSG)

**i. Text to translate (Semi-structured interview Guide)**

**[from source, English to target, Twi]**



**ii. Ask another translator to do back translation (from Twi to English)**



**iii. Compare back-translation to the original text, looking for meaning differences.**

Appendix 17: Stages of Back-translation of transcription

**Stages of back-translation for transcription**

**i. Text to translate (Transcription)**

**[from source, Twi to target, English]**

↓

**ii. Ask three translators to do back translation (from Twi to English)**

↓

**iii. Compare back-translation to the original text, looking for meaning differences.**

↓

**iv. Review to reflect the meaning of the audio recorded data at source**

