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SCHOOL OF NURSING

COLLEGE OF HEALTH SCIENCES

UNIVERSITY OF GHANA, LEGON

EXPERIENCES OF CAREGIVERS OF INDIVIDUALS WITH SCHIZOPHRENIA IN THE ACCRA METROPOLIS

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THIS THESIS IS SUBMITTED TO THE UNIVERSITY OF GHANA, LEGON IN PARTIAL FULFILLMENT OF THE REQUIREMENT FOR THE AWARD OF MPHIL NURSING DEGREE

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DECLARATION

I hereby declare that except for references to other people's works which had been duly acknowledged, this thesis is the outcome of my own original research. None of the materials in this write up has been presented either in whole or in part to any other institution for the award of any degree or certificate.

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ABSTRACT

Background*:* This research explores the experiences of caregivers of individuals with schizophrenia in the Accra metropolis. A review of the literature surrounding the experiences of caregivers of individuals with schizophrenia illustrated that this topic is widely researched globally except Ghana. Nevertheless, there is paucity of literature involving caregivers of individuals with schizophrenia in the Accra metropolis, making the area of psychiatric research largely neglected in the country.

Method: The researcher uses an exploratory descriptive qualitative design for the study.

Sample Size: the study comprised of twelve (12) caregivers of individuals with schizophrenia.

Sampling Technique: a purposive sampling technique was employed to select participants for the study.

Data collection: The researcher conducted one to one in-depth interviews.

Data Analysis: The researcher was guided by Miles and Huberman's 1994 framework of thematic content analysis.

Ethical Approval: ethical approval for the study was sought from the institutional review board of the Noguchi Memorial Institute for Medical Research at the University of Ghana, Legon for ethical clearance and approval. Permission letter was sent to the Pantang hospital's ethical review board for site approval.

Consent: consent for this study was obtained from participants.

Conclusion: base on the findings, recommendations were made on nursing research, nursing administration and nursing research.

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DEDICATION

This work is dedicated to the Almighty God for having brought me this far. It is also dedicated to my dear husband Mr. Samuel Kuru Darko, my daughter, Akosua Darko and to my mother Madam Gladys Asabea.

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CHAPTER ONE

1.0 Introduction

This chapter gives an overview of the problem under investigation. It covers the background of the study; statement of the problem, purpose of the study, the main and specific objectives, significance and operational terms of the study.

1.1 Background of the Study

Schizophrenia is a severe form of mental illness that affects about 7 per 1,000 of the adult population, most of them between the ages of 15 and 35 years. The World Health Organization (W.H.O.), (2010) estimates that globally about 29 million people have schizophrenia. Although its incidence is low (3 per 10,000), its prevalence is high due to the chronicity of this illness (World Health Organization, 2010). The onset of schizophrenia usually occurs in adolescence and early adult life (Fujino, and Okamur, 2009). Therefore, it is a long term and often a debilitating psychiatric illness that affect the quality of life of individuals with schizophrenia and their families.

Studies suggest that about 20% of people with schizophrenia show unremitting symptoms and increasing disability while around 35% of them show a mixed pattern with varying degrees of remission and exacerbations of different lengths Chien, Chan, Morrissey, (2007).

Over the years, community care for psychiatric patients is becoming increasingly common with the advent of deinstitutionalization. Most persons with schizophrenia are now being cared for in the community within small groups, homes or by their families. Studies show that in western countries, about 25%–50% of persons with schizophrenia

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stay with their families after discharge from hospital and depend on the assistance and continued involvement of their families Chien et al (2007).

Caregivers are the main support system of care for individuals with schizophrenia at home (W.H.O, 2010). In India, the National Alliance on Mental Illness (2008) reported that about two-thirds (69%) of caregivers provided care for their ill relatives. The trend of deinstitutionalization however places considerable burden for family caregivers who take on the role and responsibility of caring for their family members with schizophrenia. Burden on the caregiver refers to the consequences for those in close contact with a severely disturbed person with mental health problems. Son, Erno, Shea, Femia, Zarit, and Stephens, (2007) some authors further distinguish between objective and subjective burden. Objective burden relates to the patient's symptoms, behaviour, and socio demographic characteristics, and factors such as changes in household routine, family or social relations, work, leisure time, and physical health. Subjective burden is the mental health and subjective psychological distress among family members Reine, Lancon, Simeoni, Duplan, Auquier, (2003).

From the 1970s to 1980s, the term caregiver burden has been used to describe the adverse consequences of mental disorders for family caregivers. Caregivers' burden has been studied for determining the feasibility of discharging a patient into community or to refine the concept of care giving and its underlying structure and contents Chien et al., (2007). There can be significant changes in the family dynamics and relationships during the acute phase of the illness, as well as the ongoing care demands over time.

Many studies have shown that caregivers of individuals with schizophrenia perceived high levels of burden Foldemo, Gullberg, Ek, and Bogren, (2005); Gutiérrez-Maldonado,

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(2005); Hanzawa, Tanaka, Inadomi, Urata and Ohta, (2008). They are overburdened with continuous demands and responsibilities (Donnelly, 2001) which impact on caregiver‘s health, leisure time, and employment (National Institute for Health and Clinical Excellence, 2009). Caring is a professional concept that befits health professionals such as nurses but when care is adopted by family members and loved ones; it denotes the involvement of psychological, emotional, and physical consequences.

With regard to caregiver burden, Mwinituo and Mills, (2006) found relentless physical care giving among blood relations of AIDS patients who reported of exhaustion, anxiety and depression which resulted in their loss of jobs and their self employment activities. A study of Hong Kong Chinese families found that much of the burden was related to stigma and lack of mental health and rehabilitation services. The consequences of care included social isolation of the families and financial difficulties. Subjective burden resulting from social stigma included frustration, anxiety, low self-esteem, and helplessness. A study in Malaysia by Chang and Horrocks (2006) found that family caregivers have to cope with the impact of stigma of their relatives' mental illnesses.

Family members of a patient with chronic schizophrenia have multiple needs. The major concerns and support needs of individuals who assume this stressful role include obtaining support, reducing risks to their own well-being, and promoting the well-being of the mentally ill. Jagannathan, Thirthalli, Hamza, Hariprasad, Nagendra, and Gangadhar (2011).

If family caregivers cannot provide appropriate care, their family member with schizophrenia will be vulnerable to relapse and readmission Chien and Norman, (2003).

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Client relapse and readmissions are common with schizophrenia, but poorly supported family care giving can increase the frequency and duration of this poorer longitudinal course (Chan & Yu, 2004; Martens & Addington, 2001).

Hence, Chang et al., (2006) reported various aspects of impact on caregivers, including the economic burden related to the need to support the individuals and the loss of productivity of the family unit, as well as emotional reactions to the individual‘s illness such as guilt, a feeling of loss and fear about the future. The stress of coping with disturbed behaviour of the patient, the disruption of household routine, problems of coping with social withdrawal or awkward interpersonal behaviour of the patient, and the curtailment of social activities of the caregiver, results in depression Chang et al., (2006).

In Recognition that caregivers' burden is a global issue, the World Federation of Mental Health has issued a report supporting that caring for those with a chronic condition requires tireless effort, energy, and empathy and indisputably greatly impacts the daily lives of caregivers. Many often, family caregivers receive little recognition for this valuable work, and policies in most countries do not provide financial support for the care services they provide.

As caregivers struggle to balance work, family, and care giving, their own physical and mental health is often ignored. In combination with the lack of personal, financial and emotional resources, many caregivers often experience stress, depression, and/or anxiety in the year after care giving begins (World Federation of Mental Health 2010, Mwinituo & Mill, 2006).

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The adverse consequences of taking care of relatives with severe mental illnesses have been studied since early 1950s, when psychiatric institutions began discharging patients to the community (Chan, Mackenzie, Ng, & Leung, 2000; Reine et al., (2003). In recent years, the view of care giving burden has been broadened to involve the physical, psychological, social, and financial problems experienced by caregivers for a relative with a chronic or mental illness. This view has been accepted by the global community (World Federation of Mental Health, 2010).

Research evidence from different countries on caregivers of persons with schizophrenia generally support that there is inadequate help and support to family caregivers (Chan, Yip, Tso, Cheng, & Tam, 2009). Research has also consistently indicated that caregivers report high levels of burden related to caring for their mentally ill family members. Family caregivers' mental health may become seriously impaired (Cuijpers & Stam, 2000). Many family caregivers reported not having the knowledge and skills necessary to take on the responsibilities of care giving for their relatives. Thus, they are unable to cope with a considerable amount of the caring roles and responsibilities (Chan et al., 2009).

Physical health is also influenced by care giving stressors (Pinquart & Sörensen, 2007). Caregivers exposed to chronically stressful conditions are likely to go on to develop physical symptoms or syndromes (Grant et al., 2002). Studies have revealed complex relationships between caregivers burden and coping, social support, depressive symptoms, and physical health among family caregivers of individuals with schizophrenia and other mental illnesses. Caregivers not only face the daily stressors of unpredictable and bizarre behaviours of their relative with schizophrenia, but also emotional frustrations such as

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guilt and loneliness, and family conflicts in the caring process. There are also the external stressors of stigma and resultant isolation from the extended family and community as a whole.

Mwinituo and Mill (2006) found that, family caregivers of AIDS patients were also stigmatised, their extended family members neglected them refused to give any support to them and their patients.

Other determinants of burden included threats, nuisance, time, and restricted social and leisure activities. Lacey, (2006) suggested that relatives should be taught to deal with the burden. They should learn how to cope with disturbing behaviour and make necessary changes in the relationship with the patient. A strategy that could reflect such increased responsibility is including the relatives in decisions regarding hospitalization. In a Swedish study (Ostman, Hansson & Andersson, 2000); family burden and participation in decision-making of relatives to both voluntarily and compulsorily admitted patients were investigated. It was found that interventions for establishing a well-functioning team approach between the relatives, the patient and the health professionals were very effective. The perceived burdens among family caregivers of people with schizophrenia have been studied in various regions and cultures. A comparative study of Euro-Americans and Latinos (Jenkins, & Schumacher, 1999) suggested that the types and levels of caregiver burden could be correlated to contextual factors including gender, ethnicity, diagnosis, and living situation. A study of Mexican Americans (Magaña, Ramírez García, Hernández, & Cortez, 2007) report that between 12% and 18% of family caregivers meet the cut off for being at risk of depression. Younger caregiver age, lower levels of caregivers' education, and higher levels of the patients' mental illness

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symptoms were predictive of higher levels of caregivers' depressive symptoms. Canive et al. (1996) in a Spanish study described several major effects of caring, which included poor health of family members, disruptions to social and leisure activities and domestic routines, and reduction in household income. This finding was confirm by Mwinituo and Mills (2006) in a Ghanaian study on informal caregivers for AIDS patients where the caregivers reported loss of jobs resulting in financial difficulties but still were obligated to care.

Furthermore, caregivers' perceived stigma was significantly related to caregivers' depressive symptoms. A study from the United State of America by (Biegel, Milligan, Putnam, Song, 2004) described that the frequency of client behavioural symptoms and the lower the amount of perceived support from family members, the higher the level of overall caregiver burden.

Unfortunately, mental health has been shunned in Africa; several reports disclose a higher prevalence of stigma in care giving in developing countries than in first world countries (Chan et al., 2009). Africa has only fifty percent of its countries having a mental health policy, and if they do have a law, it is usually obsolete (Aggarwal, Avasthi, Kumar, & Grover, 2011). Ninety percent of African countries have less than one psychiatrist per 100,000 people, and seventy percent of the countries allocate the mental health sector with less than one percent of the total health budget (Bird et al, 2010). Less than sixty percent of African countries have community mental health care while the rest are focused on psychiatric hospitals (Aggarwal et al, 2010).

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In South Africa until the late 90s, mental health services were run parallel to other health-care services, and only with the implementation of the primary health care approach was the mental health component integrated into the rest of the healthcare system (Sreeja, Sandhya, Rakesh, & Singh, 2009). This transformation of the national healthcare system included the process of deinstitutionalization which was defined as the replacement of long-stay psychiatric hospitals with smaller, less isolated, community-based alternatives for the care of people with mental illness that involved the release of individuals with chronic mental illness into the community (Sreeja et al, 2009). The deinstitutionalization in South Africa resulted in families becoming the main providers of care, with health-care professionals playing a secondary role hence, family caregivers have become the primary persons involved in the well-being of individuals with schizophrenia (Sreeja et al, 2009).

Available information in Uganda (east Africa) indicates that a majority of psychiatric patients are cared for by the family who tend to have psychological and social problems (Sreeja et al, 2009). these problems were often work-related issues, stigma, marital problems, and problems with neighbours (Stanley, & Shwetha, 2006). In Nigeria (West Africa), mentally ill patients spend their life in continuous or prolonged hospitalization because of societal discrimination and community isolation. This results in family caregivers hiding and or rejecting their mentally ill relative (Baronet, 2003).

In Ghana, with a population estimate of 24,791,073, about 2,816,000 individuals are diagnosed as suffering from moderate to severe mental illness with only 32,947 representing 1.17% receiving treatment from the three psychiatric hospitals. The remaining 2,783,052.8 (98.83%) are cared for in one way or the other by family members

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(Central Intelligence Agency of Ghana, 2011). To buttress this point, Roberts, Asare, Mogan, Adjase and Osei (2013) on mental health system in Ghana, found that total health budget allocates only 3.4% to psychiatric hospitals. Statistics have shown that there is only one psychiatrist per 1.5 million people in the whole of Ghana, and the three major psychiatric hospitals which are ironically located only in the southern sector of Ghana are also under-financed, congested, and under-staffed, the study also revealed that limited beds at the three main psychiatric hospitals and the delays associated with feeding grants for psychiatric patients from central government to psychiatric hospitals has resulted in over 60% cut down in patients admissions. The family therefore becomes custodians of those without access to the psychiatric hospitals (Roberts et al., 2013). Basic Needs, a nongovernmental organization (NGO) in mental health in Ghana, in 2010, reported in their newsletter issue 1 that, policy-makers seem to have little concern for mental health, and focus more on physical health and population mortality. Caregivers of schizophrenics in Ghana suffer discrimination, exclusion and an ancient demeaning stigma (Roberts et al., 2013). The demands for care giving can bring significant levels of stress for the career and can affect their overall quality of life including work, socializing and relationships. Research into the impact of care giving showed that one-third to one-half of caregivers of schizophrenics suffer significant psychological distress and experience higher rates of social and mental ill health than the general population (Roberts et al., 2013). Central Intelligence Agency of Ghana, (2011).identified four main reasons as to why Ghanaian families make a commitment to care for their mentally sick relative and found out that families are obligated to care; are owners of their difficulties; should protect vulnerable members of their family; and are self-reliant units. These commitments can over-tax the family resources and lead to significant caregiver burden.

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The essence of the current study is to investigate the experiences and impact of physical and mental health of caregivers of schizophrenic patients.

1.2 Statement of the problem

There is inadequacy of formal caregivers for psychiatric patients in Ghana. The formal sector available to psychiatric hospitals has been stated in point 1.2.1

1.2.1 Human resources in Ghana's mental health care system in 2011

Comparing the staff strength available to all the three psychiatric hospitals and the number needed to sustain mental health per the population in Ghana, there seem wide gaps. Currently, there are eleven psychiatrists, six hundred psychiatric nurses, one hundred and twenty on the job trained community psychiatric nurses, three psychologists, one on the job trained occupational therapist, and three psychiatric social workers. Statistically, Ghana needs eighty psychiatrists, three thousand psychiatric nurses, eighty psychologists, one hundred and ten occupational therapist and fifteen psychiatric social workers.

Ironically, this number is distributed among the three main psychiatric hospitals in the country except for the community psychiatric nurses who work at psychiatric wings of general hospitals. These figures support the common usage of family caregivers being the primary source of ongoing care for their mentally ill relatives. Officially, Ghana does not have trained community psychiatric nurses, so the numbers quoted above, are all on the job trained. The mental health bill which has just been passed by Ghana's parliament advocates for deinstitutionalization of mental health care to be community based but has no trained community psychiatric nurses. This again points to the family being

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responsible for caring for their member with psychiatric conditions. Available statistics at the Pantang hospital, which is one of the three hospitals in the country has schizophrenia as the leading admission diagnosis and also associated with the highest family neglect due to community stigma. Although these statistics are telling, it does not help health professionals to understand the day by day experiences of family caregivers. Without this knowledge it is difficult to develop strategies and interventions to support family caregivers. This study therefore investigated the day to day experiences of caregivers of individuals with schizophrenia, their perceptions of impacts on their physical and mental health and what was and/or could be helpful in providing support for them.

1.3 Purpose of the Study

The purpose of this study was to document the experiences of caregivers of individuals with schizophrenia in order to inform new strategies to support Ghanaian family members.

1.4 Objectives of the study

Main Objective

The main objective of this study was to state the care giving experiences of informal caregivers in the provision of care to their schizophrenic family member.

Specific objectives

The specific objectives are to;

1. describe the experiences of the caregivers for their schizophrenic relatives
2. explain family caregivers' perceptions of what is or could be helpful in supporting their efforts to care for their schizophrenic relative.

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3. determine family caregivers' perceptions of the impact of caring on the caregivers' physical and mental health within the Ghanaian context.
4. describe caregivers' perceptions of care burden, needs and how caregivers cope and the degree of social support available to the family.

1.5 Research Questions

These objectives mentioned above, translates to the following research questions

1. What are the experiences of the informal caregivers or the burden of care giving on their physical and mental health?
2. How do caregivers perceive their role in supporting or caring for their schizophrenic family member?
3. How do caregivers cope with the demand of care giving for their schizophrenic family member?
4. What has been or could be helpful in supporting caregivers' care giving roles in mental health Services

1.6 Significance of the study

1. Findings of this study will provide nursing knowledge to develop and test new strategies to improve support for family caregivers.
2. The study will provide knowledge of caregivers experiences to policy makers
3. This descriptive study will create a rich text that will pave the way for further qualitative research on the experiences of caregivers, such as grounded theory approaches to further investigate care giving and caregiver burden in Ghana

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1.7 Operational Definitions

Caregivers: informal family member identified as the primary career for the individual with schizophrenia.

Individuals with schizophrenia: patients who have been diagnosed and discharged from a mental hospital and staying with a family member.

Experience: everyday encounters in life.

Caregivers' health: somatic and psychological discomforts experienced by caregivers in their care given roles

Psychiatric outpatient department- the psychiatric outpatient department where the researcher identified her participants.

Summary

This chapter has provided an introduction and background to the study, experiences of caregivers of individuals with schizophrenia. A brief introduction of the background to the research problem in relation to the national and global problem of informal care giving was presented. The significance of the study to policy makers, the impact on clinical practice and its improvement on the treatment of discharged schizophrenic patients were also highlighted. The purpose of the research and its objectives and definition of key concepts were equally started. Chapter Two presents a discussion on the literature reviewed.

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CHAPTER TWO

LITERATURE REVIEW

2.0 Introduction

A literature review provides a background of current knowledge on a topic and highlights the necessity for new studies (Polit & Beck 2010). The aim of this literature review is to identify and examine research previously undertaken surrounding the experiences of caregivers of individuals with schizophrenia. To obtain the research articles used in this review, electronic searches were carried out using online databases such as CINHAL, Pubmed, Hinari, dogpile, Google searches, and searches from articles from relevant journals.

The literature review is divided into 6 sections, which include family caregivers, depressive symptoms, physical health, burden, coping, and social support.

2.1 Family Caregivers

This section includes definition of family caregivers and family caregivers of individuals with schizophrenia.

2.1.1 Definition of Family Caregivers

A caregiver is defined as anyone who provides assistance to another in need (Larsen & Lubkin, 2006, p.191). Larsen and Lubkin (2006) defined the informal caregiver as anyone who provides care without pay and who usually has personal ties to the care recipient. The informal caregiver is a term used interchangeable with the family caregiver and can include family, friends or neighbors. The family caregiver also faces the demands of his or her own employment and other family responsibilities apart from those of caregiving

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(Larsen and Lubkin 2006). Dorian, Garcia, Lopez, & Hernandez (2008) use the term primary caregiver and expand the definition to cover the contact time that is ‒a primary caregiver was defined as the relative with the greatest responsibility in caring for the patient and who had personal contact with the patient at least once a week'' (p.218).

This study will use the term family caregiver to define as family member who is the primary caregiver and has the responsibility to take care of their relatives with schizophrenia such as parents, spouse, sibling, son, daughter, nephew, niece, or relative who live with their ill relatives with schizophrenia and unpaid in care giving.

2.1.2 Family Caregivers of Individuals with Schizophrenia

Family caregivers were closely involved in the illness process as most of the individuals with schizophrenia live with families at home (Chadda, Singh & Ganguly, 2007).

Family caregivers have a role and responsibility as main providers of care and support to individuals with schizophrenia. Nimnuan (2004) reported that caregivers of individuals with schizophrenia provided the over all of psychiatric care giving activity at a high level. In addition, most of the caregivers had long-term duration of care for more than ten years (Chadda et al., 2007; Fujino & Okamura, 2009; National Alliance on Mental Illness, (2008).

Numerous studies on caregivers of individuals with schizophrenia have demonstrated caregivers characteristics that most of them were female (Chen & Greenberg, 2004; Creado, Parkar & Kamath, 2006; Grandón, Jenaro & Lemos, 2008; Hamada et al., 2003;

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Laidlaw, Coverdale, Falloon, & Kydd, 2002; Magliano et al., 1998; Parabiaghi et al., 2007; Roick et al., 2007; Scazufca & Kuipers, 1999; Schene et al.,1998.). This reflects that a woman is the major caregiver in a family. However, two studies found that most family caregivers of individuals with schizophrenia were male (Dorian et al., 2008).

Studies on family caregivers of individuals with schizophrenia have also shown that most caregivers were parents, spouses, fathers, siblings and partners. (Chen & Greenberg, 2004; Dorian et al., 2008; Magliano et al., 1998; National Alliance on Mental Illness, 2008; Laidlaw et al., 2002; Marom, Munitz, Jones, Weizman, & Hermesh, 2005; Ochoa et al., 2008; Parabiaghi et al., 2007; Roick et al., 2007; Schene et al., 1998.), and their relationship with the individuals is mother (Grandón et al., 2008; Hamada et al., 2003).

Several studies have found that the mean age of the caregivers of individuals with schizophrenia was majority in the middle aged (Chen & Greenberg, 2004; Dorian et al., 2008; Grandón et al., 2008; Laidlaw et al., 2002; Scazufca & Kuipers, 1999; Schene et al., 1998). These results may congruent with the above findings that most of them are parents. In addition, four studies reported that the majority of caregivers were married (Chen & Greenberg, 2004; Parabiaghi et al., 2007; Sreeja et al., 2009).

Empirically, it has been shown that education levels of caregivers of individuals with schizophrenia ranged from not completed a secondary school to have a graduate degree (Chen & Greenberg, 2004; Dorian et al., 2008.). Studies indicated that most caregivers were unemployed and retired (Creado et al., 2006; Stengård et al., 2000).

In summary, family caregivers of individuals with schizophrenia have a major role in providing assistance and involvement in caring for individuals with schizophrenia. Most

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caregivers in other countries as well as in Ghana have similar characteristics such as parents, female, mother, middle age, and unemployed.

2.2 Depressive Symptoms of family caregivers

Many expert authorities have illustrated the definition of depressive symptoms. For example, Beck (1972) defined depressive symptoms as a specific alteration in mood (sadness, loneliness, apathy); a negative self-concept associated with self-reproach and self-blame; regressive and self-punitive wishes (desires to escape, hide, or die); vegetative change (anorexia, insomnia, loss of libido); change in activity level (retardation or agitation)’’. In addition, Radloff (1977) defined depressive symptoms as –depressive mood, feelings of guilt and worthlessness, feeling of helplessness and hopelessness, psychomotor retardation, loss of appetite, and sleep disturbance. Furthermore, depressive symptoms are mental health h outcomes result from the stressors and the way an individual copes and appraises stress (Lazarus & Folkman, 1984). Robison, Fortinsky, Kleppinger, Shugrue, and Porter, (2009), used the term depressive symptomatology and defined it as a mood of sadness consisting of feelings of hopelessness and helplessness. Moreover, Vongsirimas, (2008) defined depressive symptoms as –various kinds of affective, behavioral, somatic and interpersonal alterations that accompany a chronically sad mood (p.22-23).

In conclusion, depressive symptoms can be defined as various kinds of cognitive, affective, behavioral, and somatic alterations resulted from sadness, a reaction to loss, and the way an individual appraises and copes with stress. Earlier studies have described depressive symptoms in family caregivers. Individuals with schizophrenia who have chronic and disabling conditions, and need for long- term care after discharging from

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hospital cannot perform some or all of activities to meet their day-to-day requirements for reasons of their health state which contributes to the regulation of their functioning. Therefore, their family caregivers have responsibility to initiate and perform dependent care continuously or intermittently.

Many studies have shown that caregivers of individuals with schizophrenia had depressive symptoms or depression. Martens and Addington (2001) studied the psychological well-being of family members of individuals with schizophrenia and indicated that depression was one of negative effects that often reported by the family caregivers of individuals with schizophrenia. Studies also have shown that as many as 31% (Dyck, Short, & Vitaliano, 1999) to 83% (Maglia Magliano, Marasco, Fiorillo, Malangone, Guarneri, Maj, 2002) of caregivers of individuals with schizophrenia had depressive symptoms or depression. For mental illness, many studies have shown that caregivers of individuals with mental illness had depressive symptoms or depression. Two studies on caregivers of individuals with mental illness reported that caregivers had low to moderate levels of distress and depression (Rauktis, Koeske, & Tereshko, 1995) and 45% of the family caregivers were at risk of depression (Song, 1998). A similar view was expressed in a qualitative work by Morny (2003) in Ghana on the effects of the stigma experiences of chronic psychiatric patients at the Pantang psychiatric hospital, the same setting for this present study and found that the mentally ill and their caregivers are discriminated and stigmatized by healthcare providers, relatives, employers, coworkers, colleagues and church members in such manner as disregarding their opinions, relieving them from their jobs and discriminating against them where ever it is known that they were once a mental patient or that they are caregivers of a mental patient.

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In summary, there are a lot of evidences supported that caregivers of individuals with schizophrenia and other mental illness experienced depressive symptoms or depression. However, there are few published data on depressive symptoms among family caregivers of individuals with schizophrenia in western countries and in the context of the Ghanaian culture. Thus, it needs to be further investigated.

2.3 Physical Health

This section consists of definition of caregivers' physical health, physical health in caregiver, and physical health and depressive symptom.

2.3.1 Definition of Physical Health

Physical health is defined as the caregiver's perception of his or her health (Son, Erno, Shea, Femia, Zarit, & Stephens, 2007). In addition, physical health may be defined as an individual's ability to –fully carry out customary or expected duties for his or her age, sex, and social roles in his or her society (Brazil, Bainbridge, & Rodriguez, 2010). In this study, physical health will be defined as the caregiver's perception of his or her overall physical health.

2.3.2 Physical Health in Family Caregivers

Empirically, it has been shown that family caregivers who have the responsibility in taking care of chronically ill family members at home reported declining physical health (Chang et al., 2009; Grant et al., 2002; Harwood et al., 2000; Schulz et al., 1995). These studies indicate that providing care for family member with chronic illness at home has negatively related to physical health. Studies reported that both physical and mental health of caregivers declined significantly (Baumgarten, Hanley, Infante-Rivard, Battista,

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Becker, & Gauthier, 1994., Chang et al., 2009; 1999). In addition, Schulz and Beach, (1999) studied the caregiver health effects of 392 older spousal caregivers and reported that caregivers who were providing care and experiencing caregiver strain had mortality risks that were 63% higher than non care giving controls. Schulz et al. (1995) review literatures published in five years to examine the prevalence, correlates, and causes on psychiatric and physical morbidity effects of dementia care giving. They reported that the percentage of respondents rating their health as fair or poor in six studies which ranged from 18% to 45%, with a median of 31%. Furthermore, two studies reported that almost two thirds (63%) of caregivers of individuals with chronic mental illness reported their health as good to excellent, while the remaining one third (37%) of caregivers reported their health as fair or poor Schulz et al. (1995). The effect of care giving on physical health can be explained by physiological and psychological conditions of caregivers Schulz et al. (1995). Care giving may impact physical health by producing alterations in the sympathoadrenalmedullary axis (Grant, 1999), which is activated in the presence of a stressor. Short-term activation of this system results in a rise in plasma epinephrine and nor epinephrine, which in turn act to speed metabolism, alter immune functioning, and increase heart rate and blood pressure in a transient manner. However, long-term or repeated acute activation of this system, as can occur in the context of care giving, may lead to alterations in the set point of these systems that promote the development of pathophysiological conditions, (Son, Erno, Shea, Femia, Zarit, & Stephens, 2007).

For psychological condition, a decline in caregivers' physical and emotional health was due to heavy burden of care giving (Yen & Lundeen, 2006). When behavior problems result in greater feelings of overload, caregivers may have less time and energy to take

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care of their own health (Schulz & Beach, 1999; Shaw et al., 1997). Feeling more tired and depleted, they evaluate themselves as less healthy, engage in fewer health promoting behaviors, and use more health services (Son et al., 2007). Caregivers reported that physical health symptoms increased by one- third when comparing their physical health status between the past year and the year prior to care giving (Strobino, 2001). Two studies indicated that caregivers often experience several physical problems including back problems, arthritis, and high blood pressure (Juratovac, 2009). Other health conditions were described by caregivers such as gastric ulcers, headaches, fatigue, breathing problems, endocrine problems, and overweight. Several caregivers identified more than one health condition (Juratovac, 2009). Creado, Parkar, and Kamath, (2006) also reported that high proportions of caregiver (68.8%) experienced at least one physical problem in one year before the study. However, approximately 12% of the caregivers had used outpatient and other services in that year. It may be due to caregivers often neglect their own health and hide information about their health problems (Ward-Griffin & McKeever, 2000). In addition, physical health effects may be more difficult to detect because they take longer to develop and may not appear until after the care giving role has been relinquished (Schulz, & Beach, 1999). Whereas Baumgarten et al. (1992) did find that caregivers reported more physical symptoms than comparison subjects, consistent with their findings of increased medication use and poorer perceived health. Although most studies reported the effects of care giving on physical health in Alzheimer‘s disease or dementia caregivers, the physical health conditions receive increasing attention in other mental illness. Family caregivers of individuals with schizophrenia may potentially at risk for declining physical health because they also provide care to their chronically ill relative at home and experiences high burden and depressive symptoms. Especially the onset of disease in late adolescent and early

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adulthood may take the longer care and impact on their health than Alzheimer‘s disease or dementia caregivers.

2.3.3 Physical Health and Depressive Symptoms

Several studies have found the relationship between depressive symptoms and health outcomes. Family caregivers of individuals with chronic illness reported a negatively correlation between depressive symptoms and health outcomes (Covinsky et al., 2003; Harwood et al., 2000; Mitrani et al., 2006.). Harwood et al., (2000) studied factors associated with perceived health status among 64 family caregivers of individuals with Alzheimer‘s disease. The finding showed that self-rated health was negatively correlated with depressive symptoms. Therefore, high level of depression tends to result in poor physical function.

In summary, there are a lot of evidences supported that caregivers of individuals with schizophrenia and other mental illness experienced declined physical health. However, there are few published data on physical health among family caregivers of individuals with schizophrenia in western countries and in the Ghanaian culture. Thus, it needs to be further investigated.

2.4 Burden

This section consists of the definition of caregiver burden, burden in caregiver of individual with schizophrenia, type of burden, burden and depressive symptom, burden and physical health.

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2.4.1 Burden in Caregivers of Individual with Schizophrenia

Family caregivers of individuals with schizophrenia are actively participating in the care of their ill relatives. Schizophrenia places a heavy burden on individuals and their family caregivers, as well as potentially large demands on the healthcare system (Addington, Collins, McCleery & Addington, 2005). In most cultures, caregiving relatives are important for providing care to individuals with schizophrenia (Addington, Collins, McCleery & Addington, 2005), such as looking after the individual‘s daily needs, supervising medication, accompanying the individual to the hospital, and liaising with hospital staff Nehra, Chakrabarti, Kulhara, & Sharma, (2005). The effects of caring for an individual with psychiatric illness have typically been conceived of and studied in terms of caregiver burden. Burden is a common problem of families that have a member with schizophrenia. Families experience multiple sources of burdens in caring for their ill relatives (Church, 2005). Several studies indicated that caregivers of individuals with schizophrenia perceived high levels of burden when caring for a family member with schizophrenia (Foldemo et al., 2005; Gutiérrez-Maldonado et al., 2005; Hanzawa et al., 2008; Hassan et al., 2011; Li, Lambert, & Lambert, 2007; Liu, Lambert, & Lambert, 2007; Ukpong, 2011; Yusuf). Family caregivers of individuals with schizophrenia are faced with extensive objective (burden related to the aggressive behaviour of individuals with schizophrenia) and subjective burden (burden in the relationship, threats and nuisances, hours passed with the affected, and burden in social life and leisure activities) (Lauber & Rössler, 2003).

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2.4.2 Types of family caregivers' Burden

Family caregivers of individuals with schizophrenia are long-term care providers in the community. In this major role, caregivers are exposed to various burdens. These burdens are classified into two types: objective and subjective burden.

Objective burden refers to the observable consequences on family's physical and psychological well-being due to the symptoms and behavior of individuals, such as financial difficulties, impairment of work efficiency or disruption of family routines, and constraints in social interactions (Awadalla, Ohaeri, Salih, & Tawfiq, 2005; Chien et al., 2007; Roick, Heider, Toumi, & Angermeyer, 2006). According to Awadalla et al. (2005), objective burden is the existence of problems and changes in family life (household routine, relationships, and leisure time) that occur because of the family member's care requirements. 71% of the relatives reported the disturbances in their daily routine and 64% reporting restrictions of their leisure activities (Möller-Leimkühler, 2005). Ochoa et al. (2008) studied the influence of needs, symptoms or disability of outpatients with schizophrenia on family burden. The findings revealed that the highest level of objective family burden in caregivers (belonging to the activities of daily life module) was found in areas such as meals (67%), housework (61%) and managing money (53%).

Subjective burden relates to caregiver's feelings of distress and other psychological reactions towards caring experiences, such as feelings of loss, anxiety, depression or embarrassment in social situations (Awadalla et al., 2005; Chien et al., 2007; Magliano, et al., 2005.). Ochoa et al. (2008) found that subjective family burden (belonging to the concerns module) was high in the following domains: future (99%), security (92%),

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money (90%), physical health (85%) and social life (81%). Rössler (2003) reported subjective burden among the 64 relatives of individuals with schizophrenia as follows: 23 relatives (36%) are extremely burdened, 19 (29.7%) are heavily burdened, 12 (18.8%) are moderately burdened, 9 (14.1%) were slightly burdened, and one relative has only a small burden. Very small burden and no burden could not be found.

From literature review, the concept of family burden in schizophrenia refers to a wide range of social, financial, work- and family-related stresses and psychological reactions that result from the impact of the illness Shibre et al., (2003).

Up to 83 percent of the friends and family members of individual‘s diagnosed schizophrenia experience considerable financial, emotional, and practical burdens (Ahmed, 2006). Findings of (Ahmed, 2006) revealed that the caregivers of both long term physical illness like intractable epilepsy and mental illness like schizophrenia experience high level of burden in the areas of; patient care, finance, physical and emotional burden, family relations and occupation. Therefore, burden can be classified into 6 groups: financial burden, emotional strain, burden from living with individuals with schizophrenia, occupational burden, social burden, and physical burden. Harwood, (2000), conducted a qualitative (descriptive-interpretive) study on caregiver stressors and responses, using a study sample of eleven (11) caregivers of haemodialysis patients from the London Health Service Centre (LHSC) renal Unit. Their main purpose was to explore the specific stressors caregivers of patients with chronic disease conditions experience.

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Financial Burden

Financial burden is a burden of family caregivers from difficulties with money as a result of having relatives with a mental illness. The relatives of individuals with schizophrenia reported that financial difficulties are their greatest burden (Chien et al., 2007; Pariante & Carpiniello, 1996.). Pariante and Carpiniello, (1996) reported that women caregivers, predominantly spouses and mothers had significantly more financial problems or were more often forced to devote the scarce resources they had to care for their ill relatives than male caregivers. There was also a significant association between separated, divorced and widowed relatives of both sexes and financial burden. Being a relative of an unemployed individual, individuals with negative symptoms and individuals with disorganized symptoms were all associated with marked financial burden on family members.

Occupational Burden

Occupational burden refers to problems related to work and employment. Shibre and colleague (2003) studied the illness impact on family caregivers of individuals with schizophrenia in rural Ethiopia and reported that female relatives had more experiences of difficulty in going to work or had to stop working because of the need to care for their relatives with schizophrenia. There were significant associations between being a spouse of the individuals with schizophrenia, caring for spouses who had disorganized symptoms and work-related burden. Spouses of both sexes did not differ in their work-related burden. In addition, O¨stman (2007) studied burden experienced by relatives of individuals with severe mental Illness and reported that 28% of relatives of individuals with severe mental illness had been forced to give up their own leisure time and 15% had been forced to give up their occupation. Therefore, these two studies support that family caregivers had experiences of occupational burden from caring their relatives with severe mental Illness.

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Social Burden

Social burden is a negative effects on social and interactions of family caregivers from care giving. Family caregivers who commit to care giving commonly experience disruption in their relationships with each other and people outside of the family (Cook, Hoffschmidt, Cohler, & Pickett, 1992.). Evidence indicates that the less social support a caregiver has, the more often spiritual help is used as a coping strategy (Magliano et al. 1998).

The individual‘s poor functioning may lead families to avoid close social contacts, it is likely that they feel overwhelmed by their care giving responsibility, and too exhausted to be involved in their social network. The lower availability of a social network in schizophrenia could be also related to a deficit in social competence among family members (Magliano et al., 2005). In addition, 17% of relatives of individuals with schizophrenia reported difficulties in inviting people into their home (Magliano et al., 2005). Therefore, burden limits the social relations of the caregiver (Gutiérrez-Maldonado et al., 2005). Shibre et al. (2003) studied the illness impact on family caregivers of individuals with schizophrenia and found that there was a significant association between being a parent and carrying a social burden. They also reported that relatives of female individuals with schizophrenia, unemployed individuals and of individuals with disorganized symptoms were most likely to experience a heavy social burden.

2.4.3 Burden and Depressive Symptom

There is evidence demonstrating the association between burden and depressive symptoms of caregivers of individuals with mental illness. Song et al. (1997) studied in caregivers of individuals with chronic mental illness and found that caregiver burden

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had a significant effect on caregiver depressive symptoms, with higher levels of burden associated with greater levels of caregiver depressive symptoms. They also indicated that individuals' psychosocial behavior problems may have an impact on the caregiver's level of depression because of caregiver burden. Furthermore, Oldridge & Hughes (1992) studied psychological well-being in families with a member suffering from schizophrenia and reported that subjective burden was significantly correlated with depression. In addition, Blieszner & Roberto (2010) studied in partners of individuals with mild cognitive impairment and found that high feelings of burden were significantly correlated with depressive symptoms. Two studies reported the effect of psychoeducation program (Kochaphrom, 2000; Paungladda, 2001) and one study of the Psychiatric Family Caregiving Program (Kulchai (2007) to decrease burden. However, no study has been conducted on caregivers burden related to depressive symptoms among Ghanaian family caregivers of individuals with schizophrenia.

2.4.4 Burden and Physical Health

The empirical findings show that caregivers' burden made significant contributions in explaining the caregiver physical health. Pinquart & Sörensen (2007) reviewed 176 studies on caregivers' physical health 1986 to 2006 and reported that greater caregiver burden and more severe depressive symptoms were related to worse physical health. Similarly, Chien et al.,(2007) studied the perceived burden among Chinese family caregivers of people with schizophrenia and found that family burden was significantly and negatively correlated with health status ($r = -0.50$, $p < .01$). Chang et al. (2009) studied impact of mental health and caregiver burden on family caregivers' physical health also indicated that mental health and burden were significantly associated

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with health problems. Burden and years spent in care giving predicted physical health of daughters of individuals with dementia Chien et al.,(2007)

2.5 Coping

This section consists of the definition of coping, coping in caregivers of individuals with schizophrenia, coping and depressive symptoms, and coping and physical health.

2.5.1 Coping in Caregivers of Individuals with Schizophrenia

From literature review, caregivers of individuals with schizophrenia used various kinds of coping strategies in helping them to cope with the stress of caring role such as positive communication with the individual (Magliano et al., 1998), Problem focused coping (Chadda et al., 2007; Creado et al., 2006; Scazufca & Kuipers, 1999), seek-social support (Chadda et al., 2007; Scazufca & Kuipers, 1999), ask for advice and help (from doctors, and family members or friends) (Nehra et al., 2005), emotion focused strategies (Nehra et al., 2005), fatalism (Creado et al., 2006), prayer (Shibre et al., 2003), and religions belief (Rammohan et al., 2002). In addition, Hassan et al. (2011) studied in caregivers of individuals with schizophrenia and reported that the most coping strategies used by the caregivers were self controlling, positive reappraisal and escape- avoidance. For considering each group of caregiver of individuals with schizophrenia, individuals' parents were more frequently adopted individual's social involvement and seeking spiritual help than spouses or other relatives (Magliano et al., 1998). Siblings expressed five coping patterns: avoidance, isolation, normalization, caregiving, and grieving (Staberg, Ekerwald & Hultman, 2004). Adolescent caregivers of parents with schizophrenia used talking to a sibling, friend, or another family member to deal with the presence of schizophrenia in the family. Other strategies included prayer, journaling, or quiet reflection (Valiakalayil,

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Paulson & Tibbo, 2004). The coping patterns were influenced in different ways by many factors such as time, gender, sibling order, and frequency of interaction (Staberg, et al., 2004). For example, Scazufca & Kuipers (1999) studied coping strategies in relatives of people with schizophrenia before and after psychiatric admission. Fifty patients and 50 relatives were assessed at inclusion, and 31 patients and 36 relatives at follow-up. Coping strategies were used more frequently at inclusion (after hospitalization of the patients) than at follow-up (nine months after discharge). Problem-focused coping was the strategy used more often at both assessments. Avoidance coping was strongly associated with burden, distress and high expressed emotion at both assessments. At follow-up Problem-focused (41%) and seek-social support (35%) strategies were used more frequently than avoidance (24%), following the same pattern observed at the outset. However, there was an overall reduction in the use of coping strategies over time. These literatures show that caregivers of individuals with schizophrenia adopted various kinds of both positive and negative coping strategies in helping them to face with stress from caregiving.

2.5.2 Coping and Depressive Symptom

According to Lazarus and Folkman (1984), depressive symptoms are an outcome of the way an individual copes and appraises stress. Empirically, it has been shown that depressive symptoms have been associated with coping. Hobbs (1997) studied in the caregiving mothers of individuals with schizophrenia and reported that coping had significantly direct effect on depression. For specific type of coping, Grant et al. (2002) studied in caregivers of individuals with Alzheimer and found that problem-focused coping had a significant negative direct effect on depressive symptoms. Barrowclough and Parle (1997) studied appraisal, psychological adjustment and expressed emotion in

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relatives of individuals suffering from schizophrenia and found that caregivers of individuals with schizophrenia who were prone to depression often overestimate the threat posed by the individual's illness and underestimate their own coping abilities, leading to ineffective coping.

From literature review, the empirical findings show a relationship between coping strategies and depressive symptoms in family caregivers of individuals with mental illness. However, little is known of the correlation between coping and depressive symptoms among caregivers of individuals with schizophrenia in the Ghanaian context.

2.5.3 Coping and Physical Health

There is evidence that coping is associated with physical health among caregivers of individuals with mental illness. Szmukler et al. (1996) studied caring for relatives with serious mental illness: The development of the Experience of Caregiving Inventory and reported that The Experience of Caregiving Inventory (ECI), in conjunction with coping style, predicted a large proportion of the variance in the General Health Questionnaire (GHQ). The Experience of Caregiving Inventory (ECI) and coping significantly predicted physical health.

In addition, Hilgeman, Durkin, Sun, DeCoster, Allen, Gallagher-Thompson, (2009) studied in Alzheimer's caregivers and found that resources (including coping and social support), intrapsychic strain, gender, and education were all significant predictors of negative outcomes (including physical health and depression) Furthermore, Stowell and colleagues (2001) investigated in caregivers of individuals with dementia and found that active coping was used more often than emotion coping and had more positive effects on

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the immune system. In contrast, McConaghy and Caltabiano (2005) studied in caregivers of individuals with dementia and reported that there was no significant relationship between practical forms of coping and physical health.

2.6 Social Support

This section consists of definition of social support, types of social support, sources of support**,** social support in caregivers, caregiver social support and caregiver depressive symptom.

2.6.1 Definition of Social Support

The word –social support'' does not appear in the dictionary, but the word –support" is defined as–something that sustains a person who is under trial or affliction; maintains a person by providing things necessary for existence; or provides a person or family with necessities, means, or funds" (The Concise Macqurie Dictionary, 1982). From literature review, social support concept has been defined by several scholars in numerous ways. For example, Cohen et al. (1985) defined social support as the resources that are provided by other persons. Sarason, Levine & Basham (1983) stated that social support is usually defined as the existence or availability of people on whom we can rely, people who let us know that they care, value, and love us. Similarly, social support was defined as the extent to which an individual believes that his/her needs for support, information, and feedback are fulfilled (Procidano & Heller, 1983). The actual giving, receiving and exchange of support is commonly referred to as the function of the social support House (1988). House (1988) and Heaney and Israel (2002) also defined social support as functions provided for individual through an interpersonal relation with significant person such as mother, family members, friends,

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and significant others. These functions involve four broad types of supportive behaviors or acts: emotional concern (liking, loving, and empathy), instrumental aid (material goods or direct actions on behalf of the person), information relevant to coping with environmental demands, and appraisal (information concerning how one is acting). In addition, social support was defined as an interaction involving two or more people whose purpose is to promote awareness and education, provide emotional support, and assist with problem solving (Liu, et al., 2007). Furthermore, Rungreangkulkij, Chafetz, Chesla, and Gilliss (2002) defined social support as formal and informal community resources, including all persons and institutions that the family uses to manage a stressful situation. Vrabec (1997) review literatures of social support and caregivers burden from 1980 to 1995 and proposed three aspects are common to all definitions: 1) structural aspects of the support network which are reflected by the number and composition of one‘s interpersonal ties, 2) functional types of assistance available or actually received which include emotional, appraisal, informational, and instrumental support, 3) the nature of the support which reflects: (a) satisfaction with support received, (b) the direction or degree of reciprocity between network members, and (c) whether network interaction is helpful or conflicting.

There are many definitions of social support found in the literature. All of the definitions imply positive interaction or helpful behavior provided to person in need of support. These definitions tend to be vague and simplistic and rarely specific types of relationships between the provider and the recipient or the actual needs of the recipient for support. Many theoreticians have argued that the definitions of social support are too restrictive and inadequate because the concept is multifaceted. In summary, social support is defined as the experience or the perception of family caregiver of individuals with

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schizophrenia who being cared for and guided by others as a resource availability of caregiver to manage a stressful situation in caring for individual with schizophrenia.

2.6.2 Forms of Support

Many researchers studied and identified forms of support**.** Ahmed, (2006) delineated three forms of support: 1) Aid (direct assistance-things, money, and information), 2) Affect (expression of caring, respect, and love), and 3) Affirmation (acknowledgement of the appropriateness or rightness of acts or statement). In addition, House (1981) divided the dimensions of aid into two components: instrumental or direct help and information support. Affect and affirmation were labeled emotional and appraisal support, but they were conceptually the same.

Furthermore, Lugton (1997) also provided 6 forms of support important to maintaining or changing identity: emotional support, companionship, practical health, opportunity for confiding, experiential support, and sexual identity support.

2.6.3 Types of Social Support

In general, there are four different types of social supports including emotional, informational, material and appraisal (House, 1988). First, emotional support was described as offering care or sympathy, listening to someone, or just being available to another. Next, informational support was the transmission of knowledge to another or letting another know how to obtain needed information. Then, material support or instrumental support were described as providing money or other assistance such as transportation, lending a book, and physically assisting another. Last, appraisal support was defined as providing feedback praise, or affirmations to another. Naughton (1997)

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addressed only three major aspects of social support: emotional, tangible, and informational. Researchers have often used the conceptualized of social support created by House (1988) and confirmed by others (Tilden & Weinert, 1987). The four theoretical constructs as labeled by House, are emotional, informational, instrumental, and appraisal support. These four attributes include all possible actions of social support (Langford et al., 1997). Emotional support involves the experience of feeling liked, admired, respected, or loved (Norbeck, 1981). Tangible aid, goods, or services define instrumental support Providing information during a time of stress is informational support. Appraisal support affirms one‘s action or statements (House, 1988).

2.6.4 Sources of Support

Sources of social support include family members, spouse, parent, relative, friends, neighbors, co-workers, teacher, work and school colleagues, program leaders, other participants, community, etc. Support from family members and friends may be valued to facilitate the emotional and tangible support, but they may not be the best resources for information needed to facilitate effective coping in a given situation (Underwood, 2000; Gallant, 2003). In addition, mental health professionals can be a source of formal support to family members (Chen & Greenberg, 2004). Professional support, in particular, practical advice on managing disruptive behaviors reduced objective burden (Reinhard, 1994). Social support networks provide varieties of mental and physical assistance during times of need and crisis. Social support networks can be important in helping people change unhealthy lifestyle habits, such as excessive drinking, or in adopting new habits (Nemade et al., 2007).

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2.6.5 Social Support and Depressive Symptoms

Many studies have shown that there were the relationships between caregiver social support and caregiver depressive symptom in caregivers who care for individuals with mental illness. Social support is one of the most well-studied sociological factors that helps prevent (or buffer against) depression (Nemade et al., 2007). The National Institute for Health and Clinical Excellence (2009) reported that without social support, caregivers may feel overwhelmed and unable to cope, which may lead to a breakdown in the relationship between the family and the individual with schizophrenia, or to the caregivers experiencing anxiety or depression. Rauktis et al. (1995) also reported that social support had inverse relationships with distress and depression. In addition, Song et al. (1997) studied predictors of depressive symptomatology among lower social class caregivers of individuals with chronic mental illness and found that support from caregivers' networks and the quality of their relationship with health providers was strongly associated with caregiver depressive symptoms. The higher the levels of overall social support the caregivers received, the lower their levels of depressive symptomatology. People with stronger support systems which provide instrumental and/or emotional support have fewer depressive symptoms. In addition, the individuals' psychosocial behavior problems may have an impact on the caregiver's level of depression because of the less availability of social supports. Moreover, Yen and Lundeen (2006) studied the association between meaning of care giving, perceived social support and level of depression of Taiwanese caregivers of individuals with mentally ill and reported that perceived social support significantly predicted caregivers' level of depression. Furthermore, Tsai and Jirovec (2005) studied the relationships between depression and other outcomes of chronic illness care giving. The result showed that social support was associated with depression ($r = -.24$, $p<.01$). Social support was

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predicted by gender and depression that was males and depressed caregivers tended to have less social support. They also indicated that low social support makes people more vulnerable to depression and depressed persons may withdraw from some aspects of life, including their social network, especially friends and non-nuclear family relatives. Haley, Lamonde, Han, Burton, and Schonwetter (2003) studied in forty caregivers of patients with dementia and 40 caregivers of patients with lung cancer. The finding revealed that greater satisfaction with social support was associated with higher life satisfaction and lower depression. In addition, Majerovitz (2007) studied predictors of burden and depression among nursing home family caregivers and found that social support were associated with lower levels of depression. Struening et al. (1995) examined the relationship between caregiver support variables and caregiver depressive symptomatology in caregivers of individuals with mental illness. Findings indicated that support from caregivers' networks and the qualities of their relationship with health providers were strongly associated with caregiver depressive symptomatology. Depressive symptoms were strongly associated with caregivers‘ emotional involvement in caregiving, support from their network, quality of their relationships with health providers, and personal orientations of mastery and self-esteem. Depressive symptoms were also strongly and positively associated with a lack of perceived support from relatives and poor relationships with mental health services providers.

2.6.6 Social Support and Physical Health

Many studies have described the relationship between caregivers social support and physical health. Pinquart and Sörensen (2007) studied 176 studies on correlates of caregiver physical health were published or presented between 1986 and spring 2006 and reported that receiving more informal and formal support were related to better physical

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health of caregivers (r = .08, p ≤ .001, and r = .10, p ≤ .001 respectively). Family caregivers were satisfied with the resources of social support when they were spousal caregivers, and they rated their own health as good. Caregiver social support, with significant predictors being relationship to the caregiver better health status (r = 0.18, p < 0.05) (Tang & Chen, 2002). As caregivers devoted more time in caring, they had less time to use emotional support. Their self perceived health got worse, and mental health declined. One study has shown the negative relationship between caregivers social support and physical health. Chang, Chiou, and Chen (2009) studied the impact of mental health and caregiver burden on family caregivers' physical health and reported that physical support (the use of transportation support, emergency help, and telephone consultation.) was negatively associated with self perceived health but positively associated with mental health and burden, number of illness symptoms, and number of chronic diseases, whereas, emotional support was positively associated with functional support but negatively related to mental health and number of illness symptoms. Pipatananond, Boontong, Hanucharnkul, Rujkorakarn, Vorapongsathorn, and Sitthimongkol, (2002), studied social support among 63 caregivers of individuals with schizophrenia at Psychiatric clinic Chiang Khum hospital. The finding showed that there was a high level of overall social support. Considering in each mode, the social support was high in social integration, attachment, reassurance of worth, opportunity of nurturance, and the obligation of guidance/assistance. Whereas, Pipatananond et al, (2002) reported that caregivers of individuals with schizophrenia had a moderate level of social support. Empirically, it has been shown that the high prevalent social support resources of caregivers of individuals with schizophrenia were health professionals (Pipatananond et al, 2002; the following were parents, family members, relatives, neighbor/colleague, and monks or priests (Pipatananond et al, 2002).

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Furthermore, Rungreangkulkij, Chafetz, Chesla and Gilliss (2002) reported that mothers had lower family resources than did relatives. Rungreangkulkij et al., (2002) again found that even though caregivers perceive a variety of support types as informational, emotional, and tangible support, the caregivers' perception of each source of support vary as they provided different degree or quality of support. In addition, Lueboonthavatchai and Lueboonthavatch (2006) studied quality of life among individuals with schizophrenia caregivers in community Bangkok Metropolis. The results showed that the caregivers' health status and social support were positively correlated to their quality of life.

The empirical findings show that social support had inverse relationships with depressive symptoms. Thus, social support significantly predicted caregivers' depressive symptoms. These research results indicated the significant of providing information regarding schizophrenia, treatment, and social support resources to provide some help to caregivers of individuals with schizophrenia. However, there is no study on relationship between social support and depressive symptoms among Thai family caregivers of individuals with schizophrenia. It indicates the nature of individuals with schizophrenia and their family caregivers' depressive symptoms. Many studies have shown that burden has a significant effect on depressive symptoms, social support had inverse relationships with depression, and coping was correlated with depressive symptoms in family caregivers of individuals with schizophrenia. Studies also emphasized that burden had a relationship with coping and social support in family caregivers of individuals with schizophrenia. Based on the studies review, there is limited evidence regarding depressive symptoms in family caregivers of individuals with schizophrenia. The result of the studies have not yet indicated the relationship between all these factors to depressive symptoms among family caregivers who providing care for individuals with schizophrenia in Thai culture.

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This study examined the pattern of relationships among the factors related to depressive symptoms in family caregivers of individuals with schizophrenia by using the Stress Process Model. The selected factor from this model was examined for the stressor that had an effect on depressive symptoms and physical health among family caregivers of individuals with schizophrenia. The literature review has been shown that burden influenced depressive symptoms and physical health. In addition, emotion-focused coping, problem-focused coping, and social support work as the mediator of burden and depressive symptoms among family caregivers of individuals with schizophrenia. The Stress Process Model helped to understand the mechanism and process of depressive symptoms among family caregivers who providing care for individuals with schizophrenia in Thai culture. The result of this study would be useful to understand the mechanism and process of depressive symptoms and provide a foundation to develop an effective intervention to help family caregivers to deal with their individuals with schizophrenia effectively.

Summary

This chapter has reviewed the existing literatures that were relevant to this present study. The researcher reviewed literature on informal caregivers of individuals with schizophrenia. The literature review assisted the researcher in further explaining the concept –informal care giving||. In the ensuing chapter, the researcher presents the research methodology of this study.

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CHAPTER THREE

METHODOLOGY

3.0 Introduction

In this chapter, the methodology employed to provide an understanding of the experiences and perceptions of informal caregivers in the provision of care to their schizophrenic family member is described. It covers the study design, research setting, population and sampling technique, data collection method, analysis of data, research rigor, and ethical considerations.

3.1 Research Design

This chapter focused on the research methodology and design selected for the study, which incorporates the overall structure of the study and the techniques used for data collection and analysis (Polit & Beck 2010). Bowling (2002) highlights the importance of choosing the appropriate research method. There are two approaches used in research, qualitative and quantitative research. Qualitative research aims to help understand social phenomena in a natural rather than an experimental setting while emphasizing the experiences, attitudes, and views of the participants rather than providing quantified answers to a question (Nieswiadomy 2008). Qualitative research obtains data usually in the form of words, based on observations and interviews, rather than numbers which is the basis for quantitative research (Fawcett & Garity

2009). Qualitative research focuses on obtaining deep and meaningful information from small groups which fulfils certain criteria set out by the researcher (McCarthy &O'Sullivan 2008) and has the ability to assist with guiding future nursing practice, (Barroso 2010).

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In contrast to this, quantitative research uses numerical data to obtain information about the environment and surroundings. It is used to test theories and examine relationships between variables (Burns & Grove 2011). According to Macnee and McCabe (2008) quantitative research is unable to consider the individuality of human experience and for this reason the author believes a qualitative approach suited more for the study. A qualitative approach appears to be more suitable to explore the research question within this study; as the main focus is on establishing the experiences of informal caregivers. Parahoo (2006) identifies the benefit of qualitative research in exploring professional experiences, behaviors and practice and to contribute to the fundamentals of core nursing and health concepts. There are different research designs within qualitative research which include phenomenology, grounded theory, exploratory, and descriptive (Burns & Grove 2011). In this study, a descriptive qualitative approach will be used to explore the research question as this is well suited to the study of human experiences and will aim to gain an understanding of informal caregivers' experiences of careering for their member with schizophrenia.

The researcher, after receiving site approval from the Pantang hospital's ethical committee, chose every Wednesday to meet qualified participants because that was the day the hospital has scheduled for schizophrenic reviews. The researcher identified participants using the inclusion criterion, she explained the objectives of the study to them and participants who agreed to sign the consent form gave a date that was convenient to them for interview. Authorities at the hospital allowed the researcher to use the hospital library for the interviews and so the library was closed to users on Wednesdays. All interviews were audio taped and transcribed verbatim. Follow up interviews were done to

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clarify any misunderstanding on the part of the researcher. The researcher used six months for her data collection.

3.2 Research Setting

The study was conducted at the Pantang psychiatric hospital. The hospital is the largest among three Psychiatric Hospitals in the Republic of Ghana. The Hospital is located near the Pantang village from which it derives its name in the Ga East Municipal Assembly of the Greater Accra Region of Ghana. It has a total land area of 365 acres. It was commissioned in1975, when only partially completed by the then head of state, Mr. Kutu Acheampong. It was planned as regional psychiatric hospital to serve sub-Saharan Africa with 500 bed capacity. Well developed plan with provision for OPD (general and psychiatry), wards, administration, school, post office, police post to serve staff. There are 28 operational departments Addiction Treatment and Rehabilitation Unit, Occupational Therapy Department having Sewing, catering and Carpentry sections, Psychotherapy and Counselling, General and psychiatric outpatient department, HIV Counseling and Anti Retroviral Drug unit, Maternal and child welfare unit, public health unit, community psychiatric unit, psychiatric social welfare unit, Ambulance Service, research unit, Environment and Quality Assurance unit, pharmacy department, Nurses' Training College (psychiatry), Health Assistant Training School (clinical), a Post Community/Health Assistant Midwifery School.

The hospital has eight (8) wards two of which has been converted in to a paying male and female VIP wards. Each ward has fifty (50) beds except the VIP ward which has 16 beds. The hospital has a Staff Strength of 552, Nurses- 311, Ward Assistants-36, Psychiatrists-2, Medical Doctor-1 Psychologist-1, Med. Assistants-3, Med., Med. Assistant (Dental)-1,

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Occupational Therapist-1, Occupational Therapy Assistants-9, Psychiatric Welfare Officers-2, Pharmacist-3, Biomedical Scientist-3, and Biostatistician-1.

The hospital‘s Out Patient (OP) attendance for physical and psychological cases in 2011 was 38,358. General cases were 17536 with psychological OP cases having 20833 respectively. The top five psychological out-patient diagnoses in 2011 had Schizophrenia toping with16,990, Depression and Mood (affective) Disorders followed with 3,032 Epilepsy had 2,922 Mental Disorders due to Alcohol use was 2,206 and Mental Disorders due to Cannabis use came fifth with 1,774. The hospital receives Psychiatric patients from all over Ghana and from neighboring countries, namely, Benin, Burkina Faso, La Cote D‘lvoire, Nigeria and Togo. To present day many of the structures are not completed.

The Pantang hospital was chosen because of its proximity to the researcher and the large numbers of patients with schizophrenia being treated at this facility, which will help address recruitment issues.

3.3 Target Population

The target population for this study comprised of caregivers residing in the Accra metropolis, having a family member who has been previously hospitalized with a diagnosis of schizophrenia, discharged into a community, report for scheduled reviews and cared for by a family member.

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3.4 Inclusion criteria

Criteria for inclusion for the study was caregivers who are primary caregiver for patients who: (a) have been diagnosed with schizophrenia at the Pantang hospital (b) have been an inpatient at the Pantang hospital before or are currently re-hospitalized (c) the caregiver can express him/herself in Twi, English or both languages. (d) Should be residing in the Accra metropolis (e) will give consent to be a participant in the study (f) and the caregiver must be 18years or over.

3.5 Exclusion criteria

Criteria for exclusion for the study was

a) Caregivers who did not give consent to participate in the study. b) Caregivers who were not residing in the Accra metropolis

c) Caregivers who were less than 18 years of age.

d) And caregivers, who did not speak English or Twi language, were excluded from participating.

3.6 Sample Size and Sampling Technique

The population was the entire group of informal caregivers of schizophrenic patients the researcher obtained knowledge from. A selection of these individuals was taken from this population and was known as the sample (Gerrish & Lacey 2006). The sample provided the information and data for the study. According to Parahoo (2006, p. 260) non-probability samples can be useful with qualitative research as –the purpose of qualitative research is to contribute to an understanding of phenomena and the sample can be _chosen‘ to best provide the required data for the study. Within qualitative research, the main types of sampling include convenience, purposive, cluster, and

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volunteer, random and snowball (Bloom & Trice 2007). As the author specifically targeted informal caregivers, purposive sampling was used, as the sample was chosen deliberately, –on the basis that those selected can provide the necessary data for the study (Parahoo 2006, p. 268). This allowed the researcher to pick a selected group of individuals most appropriate to answer the questions and select the specific information sources required to gain insight into the research study (Burns & Grove 2011). As this research is self-funded with limited time available for the study, this sample technique and size allowed for easy access and was cost effective. An introductory letter from the school of nursing asking permission to conduct the study was given to Pantang Hospital administration introducing the researcher to the managers of the hospital who also, referred the researcher to their ethical committee who gave her clearance to enable her access to the research participants (Gerrish & Lacey 2006) copies of the site approval letter was sent to units and departments which were needed (see Appendix C). Prior to this, ethical approval (see Appendix B) was sought from the NOGUCHI MEMORIAL INSTITUTE for MEDICAL RESEAERCH (NMIMR) ethics committee within the College of Health Sciences at the University of Ghana, Legon. The researcher identified the participants at the psychiatric outpatient department (psyho opd) of the hospital on Wednesdays which was the day for schizophrenic reviews. The objectives of the study were explained to caregivers who accepted and qualified per the inclusion criterion to participate, were given a consent form (see Appendix D) was explained to them to sign. Contact telephone numbers of participants who gave their consent were taken information of the author was also made available for further information.

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3.7 Data Gathering Tool

Semi-structured interview guide was used as a data collection tool for this study. The interview guide was divided into two main sections-A and B. Section A comprised of the participants demographic data and B was questions to guide the researcher in her exploration of the day to day experiences of family caregivers of mentally ill patients (see Appendix E).

3.8 Data Gathering Procedure

Interview days and venues were at the participant‘s convenience and they also chose the date and time for interviews. English and Twi languages were used for the completion of the interviews because these two languages captured over ninety percent of the targeted participants. The interview covered issues relating to participant‘s experiences as an informal caregiver for a family member with schizophrenia.

Burns and Grove (2011, p.540) defined interviews as –structured or unstructured oral communication between the researcher and the subject, during which information is obtained for a study. The interview lasted for between 35 and 60 minutes and followed an interview schedule (Tod 2006). The interview followed the pattern of an opening introduction, guiding questions and a final, closing statement; which remained the same for each interview to ensure consistency. The guide question which was used for the interviews had emerged from the literature review conducted prior to the commencement of this research study, and was pilot tested to see if the questions could answer the research questions. Through the use of individual interviews, the author understood personal attitudes and beliefs surrounding the topic (Jackson *et al.* 2008). Burns & Grove (2011) advocate the use of a natural setting or location for a descriptive study. A

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comfortable, private room, free from interruptions was used for the duration of the interviews, the hospital library was closed to staff on Wednesdays, during which interviews were done and was free from any human interactions. The participants were reassured that confidentiality would be maintained at all times. Participants were given the opportunity to choose pseudonyms in order to ensure confidentiality. Rapport was built to ensure trusting relationship in order to make the participant feel comfortable and enable them to express their views honestly (Jackson *et al.* 2008). All interviews were audio taped with the consent of participants. The researcher kept a field note book to pen write participants' unspoken words, and mannerisms which could not be captured on tape to help during analysis.

3.9 Pilot study

Gerrish and Lacey (2006, p. 538) highlight the function of a pilot study as –a preliminary study carried out before the full research, to test out data collection instruments and other procedures. The pilot study was done to check out the feasibility of the main study, highlight any problems or issues which may arise and was conducted a few weeks before the actual study is set to be carried out (Burns & Grove 2011). The author conducted a small number of piloted interviews of three participants from the Accra psychiatric hospital (Accra mental) whose setting is similar to the proposed setting for the study to test the interview schedule, determine if any equipment required e.g. tape recorder works efficiently and to estimate the length of time the interviews will take (Gerrish & Lacey 2006). The participants used in the pilot study had similar characteristics (informal primary caregivers of schizophrenic patients) as those of the main study. The data collected from this pilot study were not included in the research findings, however the outcome was considered before commencement of the main study.

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3.10 Data Analysis

This study used Miles and Huberman‘s framework of thematic content analysis. Miles and Huberman (1994) described the major phases of data analysis to be data reduction, data display, conclusion drawing and verification. Each audio taped interview was transcribed verbatim and was used as a primary data source (Miles et al., 1994). The audio tapes of the participants’ descriptions of their experiences as informal primary caregivers for individuals with schizophrenia were then transcribed verbatim. Once the interviews were transcribed, an overall summary was written based on the participant‘s responses to the demographic questions and the research questions from each interview. The transcribed data were read over and over again to identify ideas, concepts, meanings and memos from the transcribed data and supported with verbatim quotes. Themes and sub themes were then drawn from the meanings, ideas and concepts which run through most participants‘ statements. The researcher explained each theme and or sub themes identified to give meaning to readers and supported them with verbatim quotes of` participant transcribed data.

3.11 Data management

The interview material is being kept in the researcher‘s custody and only the researcher and her supervisors have access to them. Demographic data was separated from the interviewed data and make sure that no linkages are made between them. The transcripts will be kept for at least five years after the study. Participants were allowed to choose pseudonyms of their choice to identify them with to reduce the risk of making linkages to them. All data has been kept in a locked safe and only accessible to the researcher and her two supervisors. This storage will remain in place for the requisite time of one to

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five years after which time all electronic data will be overwritten and all manual data shredded.

3.12 Research Rigor

Rigour refers to the extent to which the researcher strives for excellence and how they adhere to detail and accuracy. Parahoo (2006) highlights that although rigour can be difficult to determine in qualitative research, researchers want their findings to reflect truthfully the phenomenon they are studying and to contribute to knowledge that is beneficial to others. The researcher used the framework by Lincoln and Guba (1985) as cited in Parahoo (2006, p.410) and Polit& Beck (2010, p.492) to increase the trustworthiness of this study. This framework encompasses the following four criteria for developing trustworthiness of a qualitative study, credibility, dependability, confirmability and transferability.

Credibility: Credibility focuses on the truth and value relating to the findings of the study and the representation of these (Topping 2006). The researcher, through the use of semi-structured interviewing techniques, tape recordings of the interviews and transcriptions of verbatim quotes, increased the accuracy of the descriptions of participants' experiences and therefore increased the credibility of the findings (Streubert & Carpenter 2010).

Dependability is concerned with the ability of the data to remain stable over time, would the study findings be replicated if undertaken with similar participants in a similar context. Credibility cannot be attained in the absence of dependability. The researcher used an audit trail to enhance the dependability of the study. It involved tracking and

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recording all decisions which could influence the study so an outside individual can examine the data (Streubert et al 2010). The researcher is keeping all recordings and of all decisions regarding the study with all other information under lock and key.

Confirmability refers to the data representing the information participants provided. There were no biases or subjectivity in the study; the findings represented the participants voice (Polit & Beck 2010). The researcher upheld this principle by clarifying all information with the participants. The researcher made a follow up interviews to two participants at Adumfa and Abo Offie's prayer camps in the central and eastern regions of Ghana during the sit down strike by the pharmacy association of Ghana to confirm and clarify statements caregivers had given during interviews.

Transferability involves the extent to which the findings of a qualitative study can be useful to similar groups or situations (Parahoo 2006). The study will enhance knowledge and subsequently result in the developments and practice of care giving.

It should be understood that to achieve the robustness of study, accurate records were kept of all interviews and interactions with participants, as the careful recording of data was crucial to the study. The researcher considered at all times, strict attention to details, adhering to procedures and through consistency and accuracy throughout the research process.

3.13 Ethical Considerations

Ethical issues in research relates to the protection of human participants to ensure the absence or lessen the possibility of harm, anxiety, discomfort or trauma (Parahoo 2006). Parahoo (2006) asserts there are ethical implications at each stage of the research process

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from the choice of topic to selection of design and publication of the findings. It is ultimately the responsibility of the researcher to protect participants and conduct all research in an ethical manner. The researcher is cognizant that each research approach and every study has its own ethical implications (Parahoo 2006), therefore the researcher implemented and abode by the following ethical principles:

Autonomy: Participants were given clear unambiguous information regarding the research, comprehended the information and the option to consent or decline participation voluntarily as Polit and Beck 2010 stated. Informed consent was sought from every participant. Information sheet was also explained to all participants and were provided with copies of the consent form. Polit et al., (2007) advises the consent form should be clear, concise and easy to read with no jargon. These information sheets and consent forms were stored under lock and key and only the author and her two supervisors had access to. The researcher also explained to participants they have the right to withdraw from the study at any time.

Confidentiality: Confidentiality is essential; the researcher will safeguard participant‘s identities and responses from public disclosure (Stake, 2010). The researcher assured participants of confidentiality and were respected at all times. Pseudonyms were used throughout the study. Participants were assigned an identification number which were used throughout the study and no identifying information were entered onto computer files. Encryption technologies were used to protect electronic data in keeping with the Policy on Good Research Practice (Stake, 2010).

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Beneficence: one ethical principle in research is beneficence, where the onus is on researchers to minimize harm and maximize benefits for the participants themselves, other individuals or society as a whole (Polit and Beck 2010). The sole aim of this study was to be of benefit. The researcher is certained that this study will be of benefit to the nursing profession and subsequently improve the lives of informal caregivers of individuals with schizophrenia.

Non-maleficience: Research should not cause any harm to participants either physical or psychological (Parahoo 2006). The researcher therefore listened attentively to participants, provided opportunity for them to voice any concerns or queries they have regarding the study.

Fidelity: This involves the building of trust between the researcher and the participants (Parahoo 2006). The researcher always put the safety and well-being of the participant above the completion of the study. The researcher upheld this principle by ensuring that participants were aware they could withdraw from the study at any given time and that no information would be used within the study after one‘s withdrawal.

A research proposal was sent to the institutional review board of the Noguchi Memorial Institute for Medical Research at the University of Ghana, legon for ethical clearance and approval. Permission letter was also sent to the Pantang psychiatric hospital and all the units that were to be involved in the study. Participants were given consent forms which explained by the researcher for participants to make an informed decision.

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Summary

This chapter provided the rationale for the researcher's choice of design, setting, population and sampling technique, data collection method, pilot study, analysis of data, research rigor, and ethical considerations used in conducting this study which is a qualitative study to explore the experiences of informal primary caregivers of individuals with schizophrenia. It outlined the steps the researcher undertook to perform the study, and the ethical principles guiding the study were also outlined. Chapter four focuses on the findings of the research and the transcribed data.

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CHAPTER FOUR

FINDINGS

4.0 Introduction

This chapter presents findings on experiences of caregivers of individuals with schizophrenia in the Accra metropolis. Twelve participants in the Accra metropolis were interviewed (Appendix F) on their experiences regarding care giving for a family member with schizophrenia. In-depth interviews were conducted from November 2012 to May 2013 using an interview guide. The interviews were audio-tapped and transcribed verbatim. Content analysis was employed in addition to field notes field notes on the behaviour, mannerism and some of the reactions of the participants that could not be captured by the tape recorder. The field notes were analysed to add context to the data that provide deeper understanding and interpretation of the phenomenon investigated to attain a deeper understanding of caregivers' experiences, the transcribed data was read over and over again to identify words, ideas, memos, concepts and themes that appeared frequently. Themes, concepts and words that appeared frequently in each interview transcript. The themes, concepts, and words were compared and cross-checked with other interviews and found to be consistent and saturated by the end of the tenth participant. After obtaining saturation, more interviews were conducted as follow up interviews to clarify issues on incentives that was reported by some participants in earlier interviews. The themes and concepts identified were grouped into categories and subcategories to reflect the emerging experiences of the participants (Table 4.1). Six main themes were identified with several subthemes. The themes extrapolated from the interview data are discussed using the participants' own verbatim accounts.

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The researcher used direct quotes of participants to emphasize the issues that emerged from the themes. The participants were interviewed in numerical order and the findings are presented using pseudonyms to personalize the verbatim report and conceal the participants' identity. The pseudonyms for the participants are as follows _P1' is identified by the name Naa, _P2'as Fiadzo,_P3'as Araba, _P4' Nkansah, _P5' Sena, _P6'Kukua, _P7'Okaine, _P8' Dzifa, _P9' Serwaa, _P10' Nii, _P11' Adoma, and _P12' Ocancy. Participants' unspoken words and researcher's reflections on the findings have also been presented. The participants profile consisted of mothers giving care to their sons or daughters with schizophrenia, a father caring for his son, younger sibling providing care to his elder brother, a husband caring for his wife, a son caring for the mother, a grandchildren caring for grandparents. This mix group of caregivers participated in an in-depth interview which generated concepts, ideas, and themes until saturation was reached at the 10th person.

4.1 Saturation of the Data

According to Burns and Groove (2005) saturation in a qualitative study is related to the sample size which is usually dependant on the recruitment of the participants and subsequent thematic analysis that follows each transcribed interview or continues until no additional themes emerge from the data. In the view of Polit and Beck (2008) saturation is when the collection of qualitative data gets to a point where a sense of closure is obtained as further data yield redundant information. In the current study data saturation occurred at the 10th participant. Further, the issue of obligation to care from the 10th participant drew the researcher's mind to conduct two more interviews to clarify the issue in the phenomena under study.

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4.2 Findings of the study

The result of the study is presented in the ensuing paragraphs.

4.2.1 Description of the sample

The twelve (12) participant caregivers were aged between twenty three (23) and seventy four (74) years. They were all caregivers residing in the Accra metropolis without any training or background education in mental health care. Seven of the participants spoke in English while five spoke in Twi. Participants reside at different suburbs in the Accra metropolitan area. The caregivers consisted of seven (7) females and five (5) males. Five (5) of the participants were government workers, two (2) self employed, and two (2) retirees from the formal sector, two (2) student caregivers, and one (1) unemployed. In terms of marital status, five (5) of them were married, four (4) singles and one (1) each were separated, divorced and widowed. The caregivers were Christians from different denominations and sets of the Christian religion. All caregivers had formal education except one 70 year old caregiver who has never been to at all. The period of care giving ranged between three months to thirty years. The general profile of the participants is provided in Table 4.1. Content analysis was employed to generate themes and categories for the study.

4.2.2 General profile of participants

The characteristics of the participants obtained included the age, gender, educational background, occupation, marital status, Relationship to the patient, length of care and languages spoken (Table 4.1). The male caregivers were either providing care to their son, mother, brother, grandparent or a wife. The female caregivers were also caring for their son or daughter, cousin or an aunt.

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4.2.3 Themes and categories obtained from the interviews

From the experiences narrated by the participants, seven main themes and twenty one categories or sub themes emerged from the data analysis. The data obtained from participants were transcribed verbatim. These are presented in the following table.

Table 4.1: Themes and categories

Number	Themes	Categories
1.	caregiver burden	a) psychological burden b) economic burden **c)** physical health impact
2.	impact of care giving on social life	a) impact on marriage and relationships b) inability to attend social functions c) impact on work output d) social isolation and loneliness e) stigma
3.	beliefs about the causes of schizophrenia	a) schizophrenia as a spiritual disease b) ancestral curses c) satanic causes
4.	other outlets of treatment	a) Prayer camps b) herbalist
5.	caregiver needs	a) family support / extra hands to help in carrying b) health education c) visits from health professionals d) ignorance on condition
6.	attitudes of health professionals	a) Positive attitudes b) Negative attitudes
7	obligation to care	a) my blood relation b) no one will care c) fear that patient may be harmed by others

4.2.4 Caregiver burden

The experiences of caregivers were explored to determine the extent to which caregivers perceived their emotional, physical health, and financial status as a result of caring for their relative with schizophrenia. The caregiver burden consisted of psychological burden

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involving feelings of sadness, thinking and worrying, about the patient and his lack of recovery, and bizarre behaviours. The psychological worries and feelings were compounded by the stress of providing care and the everyday fear and panic that the patient might be harmed by outsiders for his bizarre behaviours and actions. Apart from these mental worries and difficulties, care in its self is difficult, made more so due to financial and economic problems encountered by the care giver in diverse ways. For instance, the thinking and worrying created some physical exhaustion and frustrations among the caregivers. Feelings of sadness were expressed as a mood of hopelessness resulting in reduction in caregivers' spirit. The caregivers indicated they went through periods of sadness daily knowing that they had a member with mental illness. Mothering/fathering a child that drained their energies from the childhood days of the patient to adulthood only for that child to become a schizophrenic patient was a huge lost to most of the caregivers. The diagnosis of schizophrenia alone was a huge loss to most caregivers.

Psychological burden as a sub- theme had four categories emerging from it. It included the mental or instinctive feelings of participants, feelings of sadness, thinking and worrying, stressful and difficult caring, fear of being harmed by patient, fear of patient being harmed or hurt by others, fear of who care after caregiver's death, and fear of entertaining visitors.

Findings of the study revealed that informal caregivers of patients with schizophrenia experience sadness in their care giving roles. Caregivers said they go through lots of feelings of sadness daily in the knowledge that a family member is mentally ill and so much resources is spent on them from childhood to adulthood yet they were still

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schizophrenic. They said it saddens their heart because they are not able to understand the situation. Fifty four year old Nkansah who has been caring for his wife after discharge for the past three months before our interview typified the situation as follows:

> I feel very sad because when I married her about 33years ago, she was not like this but, now she is diagnosed as a mental patient. I can‘t sleep, there are financial difficulties which she used to help me with but now I have to do everything including care for the children. The children have to go to school; I am also aging so I don‘t have much strength as before. These huge responsibilities constituted huge burden for me. I feel I am sinking in my spirit., I feel very sad deep inside me.

Mr. Okaine, a 46 year old electrical engineer caring for his brother also expressed his emotions this way:

> Seen from outside, (referring to neighbours and co-workers) I may be encouraging people who keep asking about my brother‘s health, but in my quiet moments I weep a lot because I feel so sad that my brother, a onetime medical student, has ended this way. I ask why God is not touching my brother.

A feeling of sadness was evident in the words of Madam Araba, a 54 year daycare proprietress caring for her son. She lamented:

> To take care of your child from infancy to adulthood for the child to end up as a mental patient is sad. When I look at all the expenses I have made on him as a parent and at the end of the day it comes like this is sad. I have cried a lot all this while.

Thinking and worrying was a psychological burden for the caregivers. Thinking is a cognitive experience that involves meditating on a problem or becoming mentally aware of a problem. In the view of the caregivers, the chronicity of the illness make them think and worry everyday as they are always afraid there will be nobody to continue with the care for the patient in the event that they die knowing the stressful nature of care. The following participants expressed how their minds are often full of thoughts. Master Ocancy, a 23 year old secondary school student who has been combining care giving

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with education and caring for his mother close to two years with his academic work had this to say:

> I think a lot about my mother‘s illness. It has affected me academically. I can‘t concentrate in class, I can‘t read my books. I am always thinking. I ask myself, who will take care of my mother when I am not around or when I travel these thoughts leave me thinking and thinking hoping for a solution but none comes.

Furthermore, a mother, Madam Dzifa, a 53 year old ward assistant who has been separated from her husband because of care giving role to her son for 8 years reported:

> As a mother, I am always thinking, I think a lot, I pray, and fast all the time. Seeing my child with this disgraceful condition make me feel very sad and I think a lot. I have sleepless nights due to excessive thinking. I am worried.

A component of the caregiver burden is the psychological burden of care giving and the stressful nature of caring. Psychological stress is the result of caregivers‘ cognitive appraisal of what is at stake and what can be done about it. Participants reported that they were always under stress because of the aggressive and bizarre behaviours of the patients and the insults they receive from these patients they were caring for. They indicated that they were always afraid about how people may not be aware of the mental illness of the patient and may fight and or harm them and the cost will be on them. Caregivers were inundated with frequent mental stress about how the patient might embarrass them with their bizarre behaviours when people visit them in their homes. Hence, there was a lack of interaction between them and their neighbours. To avoid this psychological stress, all caregivers turn down friends and invitations.

Madam Naa, 68 year old retired receptionist and a divorcee caring for her daughter for 30 years stated:

> Caring for a mental patient like Gifty is a whole stress. Anytime she is to take her drug, is stress. To wash her things is stress; to clean her room is stress to come for review is stress so everything about care giving is stressful especially without any professional education.

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Mr Fiadzo, a 74 year old retired electrical engineer and a father of five who has been a caregiver for his last born for the past 19 years and facing rejection from his older children stated:

> Psychologically, I will say because I am not trained, it gives me stress yes is stressful. Is very stressful, look at the patient, he is over 30yrs, when you give him medication, he will not take, when is review time, he will not come. You have to bring him yourself. The fact is, it is very stressful. The stress increases and I have sleepless nights when review date is getting closer, because I am looking at my pocket whether I have or I don't have, I have to bring him meanwhile he doesn't even accept the fact that he is a patient. Madam (referring to the researcher), as for the stress you go through you can't explained care giving is very stressful.

Coupled with the psychological burden of care giving is fear. It is the unpleasant emotion caregivers go through which usually result from the belief that someone or something dangerous can happen, or is likely to cause pain, or threat. Fear was expressed in different forms by caregivers. Fear of being harmed by patient because they are not educated on the signs and symptoms of relapse, fear of patient being harmed or hurt by others because of the aggressive and insulting behaviours of the patient, fear of continuing care after death knowing the stress one go through as an informal caregiver, and fear of entertaining visitors because of the patients bizarre behaviours.

Madam Serwaa, a 46 year old tax administrator who is combining marital life with care giving to her aunt also in her narration said:

> She gets violent at home and threatens us most times and it scares me. When she relapses, she throws stones at moving cars windscreens and I have to bear the cost. Have you noticed one of her front teeth is not there; it was a driver who beat her and broke her teeth. She refused to pay the driver after service, insulted him and also broke his windscreen. The driver didn't know she was a mental patient and so retaliated.

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Adoma, a 70 year old widow who has been caring for her son for the past eighteen years has the fear of who to continue with care after her death. She lamented:

> My fear is about who will take over the care when I am no more, I mean when I die. I am also afraid he can be harmed because when he absconded and was found after two days. Aunty (referring to the researcher), I was shocked because within that 48 hours, he had grown so lean and very dirty. Anything could have happened to him. I am afraid.

Another participant expressed:

> The fear is about the patient. I am afraid she can harm me one day she can also be harmed by neighbors because when she becomes aggressive, she is not afraid of anything.

The burden of care giving also involved physical problems that resulted in physical ailments and difficulty to cope. Some caregivers narrated the difficulty in getting these patients to take their medications. The caregivers expressed difficulty occurrences as after serving the patient meals, she will use the bowl also as a lavatory and the caregiver dares not complain else, she will receive beatings from the patient. Other participants said the patient they were caring for at times threaten to beat them when these behaviors are cautioned. Others also indicated that the patient disgraces them in the presence of visitors by calling them witches.

Madam Naa is 70 years. She is a retired receptionist and has been a caregiver for 30 years. She stated why care giving is difficult.

> Caring is difficult is not easy at all. At times after eating, she will defecate into the bowl where she ate from. When you complain she becomes angry. I give her chamber pot but she will urinate into it even if is full and also defecate on until it is full and over flowing. When you talk to her she will say if you can‘t clean, I don‘t care and as a caregiver, I have to endure all this. It makes caring very difficult for me.

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74 year old Mr. Fiadzo is a retired electrical engineer. He has been caring for his son for 19 years. He spoke sadly:

> Is difficult because this is a sick person who is not weak or bed ridden this is a strong energetic young man who think he is not sick, he gets angry at the least thing and at times very aggressive and you the person caring has not been educated on anything on the condition so is a difficult situation on finds himself which has no solution. Is like a big burden on me. A burden that I don't even have solution to which is always there and you are trying to come out of it and you can't come out of it.

Madam Araba, a 56 year old unemployed mother who has been a caregiver to her son for 11 years also told her story this way:

> Auntie (referring to the researcher), is difficult. a grownup who should be working to help his parents take care of his younger siblings, sits at one place and without any reason, starts laughing, talking to himself, gets up and start going, it makes your spirit sink.

Economic burden was also noted to be one of the caregiver burdens for most caregivers interviewed. This involves the hardships or problems encountered by caregivers in financing the treatments for their family member with schizophrenia. Most caregivers interviewed reported they encounter financing difficulties especially in the purchase of medications, feeding the patient because the psychotropic drugs make them eat a lot. Other side effects of the psychotropic medications like excessive sleep results in the inability of patient to be productive and contribute economically to their care. Some said at times they are not able to get transportation monies to send the patient for review. Other caregivers said family members who were once helping financially have withdrawn the aid because they think they are not getting any result of total healing. In a way, the experiences of caregivers also show that the financial burden is mainly bourn by the close relatives providing the care who in the process have become frustrated by the experience.

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In her frustration, Madam Serwaa stated the magnitude of the economic burden as follows:

> Is difficult especially in times of relapse because you will have to find money to move the patient for treatment otherwise I am fine. Nobody helps financially I don't even burden my husband because I work. I don't also want him to think that I have brought my auntie to the house to add to his financial burdens so I don't ask him anything concerning her health and no support from the patient's husband, children or siblings. All is me I even take care of the patient's children's up keep and their education.

The experience of some caregivers also suggested that the financial burden sometimes become higher due to shopping around alternative forms of care Madam Adoma, a widow caring for her son typified this situation as follows:

> Aunty (referring to the researcher), pastors took all my money. At a point, I sold all my cloths to pay pastors. Even those pastors who did not charge me will ask that I pledge towards their church building the prayer camp that we were at Kwabenya. For instance, the prophetesses asked for a white sheep, white calico, and vegetables of all kind. I sold my jewelries and some cloths and I did as the prophetess said later, the patient absconded from the camp. When the patient was brought, she asked me to take him away because he is a difficult patient. As for the pastors and prayer camps I visited, I can't count aunty, I have spent so much on my son's illness. I hope this burden will end soon.

Among other caregiver burdens were the issue of physical health concerns. These are said to be negative changes in the physical conditions of caregivers regarded as evidence of their care giving roles. Caregivers revealed various physical symptoms they often experience. Most caregivers interviewed said they have had hypertension as a result of their care giving roles, some said they have been knocked by moving cars and has resulted in fractured legs because they were thinking excessively and were absent minded even in the middle of the road, others said they were going through depression but nobody cares about the caregiver's health. Mr. Nkansah has been a caregiver to his wife whom he had married for 33 years for three months. She said sadly:

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> I am not in good health. When I do something small then is affecting me, I have hypertension, when I do something small, I feel tied. I had a motor accident sometime ago and broke my left ankle. I was absent minded because of excessive thinking. money to pay the children's school fees, money for the up keep of the family, money for the patient's medications and travels for review are financial burdens that resulted in the accident. Now it has affected my health physically I can't walk properly.

Kukua a 38 year old seamstress she has been a caregiver to her aunt for the past 15 years. She also narrated her health experience as follows:

> The impact of care giving on my health includes thinking; it even resulted in an accident I was knocked down by a car at Makola market. I was thinking about the patient who is a graduate and once a tutor in secondary school now reduced to a schizophrenic patient and also sent away by her husband. At times I feel pain at the site. My leg was stocked under the car; it was just by the grace of God.

In their frustration, some caregivers wished death for their –patient''. Madam Adoma, an unemployed widow indicated that to me this way:

> I have had a hypertension already from thinking because of the patient. Sometimes out of frustration I even say it would have been better if he was dead.

4.2.5 Impact of care giving on social life

Another experience of caregivers which the researcher explored was the impact of care giving on caregivers' social lives to determine how their care giving role for their relative with schizophrenia has alienated them socially and how it has affected their marriages and or other relationships. The impact of care giving on caregiver's social lives consisted of how their care giving roles affect their intimate relationships and marriages, due to the critical observations needed to handle schizophrenic patients' unpredictable tantrums and prolong recovery. Compounding this social alienation is the impact of care giving on caregivers' work out put. Lateness to work, frequent requests for permissions needed to attend to patients' urgent health needs in relapse situations, coupled with absenteeism

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to work, have resulted in numerous warning letters from their managers. Other social encounters by caregivers include social isolation, loneliness, and Stigma. The caregivers indicated they went through periods of loneliness and intentional social isolation daily knowing that they are stigmatized socially because they have a family member with mental illness. The Impact of care giving on marriages and other relationships were said to be negative for most participants both married and unmarried

Madam Dzifa a 53 year old mother of two whose 11 years of care giving to her son resulted in marital separation said:

> Care giving has affected my relationship already because we are separated as husband and wife. My husband think I am not allowing him to take him to the shrine so now he has left everything on me so my marriage has been affected now all because I am caring for my son.

Miss Sena, is a 26 year old polytechnic graduate and working as a sales manager. She is not married but in a relationship. She has been the primary caregiver to her cousin. She stated:

> Sometimes I do suspect that my boy friend can leave me because of my cousin‘s mental condition because I know the only thing keeping us together is Christian background and the fact that we fellowship in the same church otherwise he would have left me. My spirit tells me the relationship is shaky.

Mr. Ocancy, a 23 year old high school student who has also been the primary caregiver to his mother for the past 2 years had this to say:

> I am afraid to enter into intimate relationship because maybe if the lady gets to know about my mother‘s condition, she may live me or insult me with it. So I try as much as I can to avoid intimate relationships. I don‘t think I will ever get married.

Another negative effect of care giving on caregivers‘ social life is the Inability to attend social functions. Caregivers reported that they are no more able to socialize like before. The findings of the study also revealed that caregivers see themselves as becoming very

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restricted especially concerning their involvement in social activities such as funerals, weddings, naming ceremonies and the like. Some caregivers said they no more attend social gatherings/functions because they cannot leave the patient alone at home, others said whenever they are invited for any social functions, they personally do not go but ask other people to do so on their behave, many said they send gifts or donations without attending personally. Mr. Nkansah is 54 years. He doubles as a retail second hand car tyre dealer and a driver. His caring role to his 3 month care giving to his wife has affected his social life negatively. He explained:

> For now, those social responsibilities, I don‘t attend them because I can‘t leave her with the excuse that I am attending a funeral or a wedding for that I can‘t do. Her life is more important to me than funerals and weddings; I normally send donations or gifts but do not attend them. There is no hand at the moment to continue the care

The inability to attend social function was again evident in the words of 38 year old seamstress, Madam Kukua who also stated:

> I have to abandon those activities like going to weddings, funerals and festivals especially if I don‘t get anyone who to take over the care, I can‘t go. I can‘t leave her alone in the house so I neglect those responsibilities. Friends think I am out of the country but I haven‘t gone anywhere. It is my aunt‘s condition that has separated me like that.

In his statement, Mr. Fiadjo a 74 year old married electrical engineer caring for his son explained why he cannot attend those social functions:

> I have to abandon those activities like attending funerals, festivals naming ceremonies and the likes. I am the family head in my hometown and have to perform these ceremonies as tradition demands but I am not able to do them. Some of these traditional ceremonies take days to especially festivals and funerals. I can‘t also leave the patient alone with my wife who is 72 years. The patient can harm her. She is even afraid of him so I cannot leave them alone at home the result may not be good so I don‘t attend those ceremonies

Participants also revealed to the researcher about the impact of care giving on their work output. This, caregivers explained, was their inability of to have time for their work resulting in a decrease in their work output and affecting their finances. Some

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caregivers said they have stopped working because they have no one to leave the patient with and are afraid the patient can be harmed because of unnecessary verbal attacks on people. This has resulted to heavy financial burden in the home. Some said they have had several queries for lateness and absenteeism. This was evidenced in the words of 46 year old engineer, Mr. Okaine, caring for his elder brother for some 25 years now. He stated:

> Knowing the fact that there is this huge caring responsibility on my shoulder it affects my daily activities because I still have my mind in the house. I call several times to the house to check on the patient because my mother is very old and my wife, a nursing mother. On numerous occasions, I have been absent minded at very important management meetings. It is affecting my work out put seriously but what can I do my sister (referring to the researcher).

Dzifa, a ward assistant and a mother of two, caring for her son for 8 years now explained how caring is affecting her job:

> If I don‘t get anyone to take care of him I can‘t go to work because I can‘t take him to work neither can I also leave him alone in the house for work. Though my work people know I have a mentally ill son and do accept some of the excuses I give for my lateness to work and absenteeism, they will be fed up with me one day. I am lucky to be in the government sector otherwise no private firm will tolerate me. I would have been sacked because of low work out put.

Miss Sena is 26 year old polytechnic graduate. She works in her aunt’s stationery shop as a sales executive officer; she told the researcher how her care giving role is affecting her work:

> I need a helping hand to be able to concentrate on my work. My care giving role is affecting the business because any time something happen to the patient they call me. Formerly, it took several months for him to relapse but ever since he entered the university, the relapse rate has been more frequent and so are the disruptions. I am called anytime he has a problem to take him to the hospital. It is affecting my work big time.

Social isolation and loneliness was identified as one of the impact of care giving on caregivers’ social life. This is caregivers’ pervasive withdrawal or avoidance of social contact, or communication, or the act of caregivers intentional withdrawal from society.

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As a result of their care giving roles, some caregiver said they have withdrawn socially because some people in their vicinity find a way of broadcasting to others that they have a mentally sick person in their house so whatever business they do or have is stigmatized and as such not patronized. Others said some also extent the mental illness to the caregivers so with the least thing, they are insulted with mental illness. These and many others make them isolate themselves socially.

Fifty four year old Mr. Nkansah is afraid to leave his wife the patient alone in the house for fear of other people getting to know about the wife‘s present condition which has existed for the past three months. Mr. Nkansah’s statement on social isolation typified most participants.

> For now people are becoming aware of her situation because of the way she was making allegations of witchcraft about neighbors. My wife is well respected in the community; I don‘t want people to know so I am always in the house with her. People think I have travelled but no. I have intentionally isolated myself though is not the best thing to do, at the present circumstance keeping to myself being fine.

Miss Sena a 26 year old sales executive gave her reason for intentionally isolating socially.

> It‘s like you can‘t receive visitors because of the patient. Sometimes you just have to ignore or refuse invitations for social events. Honestly for some time now, I don‘t attend social functions for the media to send out information that my aunt who also occupies a political position has a son who is mentally challenged. She has as me to keep the patient away from the public so I have no choice than to withdraw from social activities because you are the caregiver and you must stay or go out with him.

One ancient canker in care giving for mental patient that caregivers had to battle with was the issue of stigma in care giving. This is caregiver‘s perceived negative attribute in care giving that causes the caregiver to feel devalued and the feeling that people tend to distance themselves from them because of their care giving role. Findings showed that, most caregivers had self stigma, caregivers also think their neighbours, health care staff

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and their extended family members also stigmatize against them. Participants also revealed that there is stigma at the work place in a very subtle manner. It was explained that when one's working colleagues are aware you have a family member with mental illness; they make sarcastic statements that hurt.

Madam Serwaa, a 46 year old tax administrator who holds a masters degree in task administration stated:

> My sister (referring to the researcher) I have told my working colleagues that my aunt is well now and have even travelled out of the country because at a point, I realised my working colleagues were making funny comments when I get angry about something, they will say are you becoming your aunt. Others also made sarcastic statements like how is your mad aunt and it was very hurting. But since I told them she is healthy and is even out of the country, those things have stopped. I no longer ask permission to take her for reviews I just find good excuses for coming to work late or absenting myself.

Miss Sena again had this to say:

> It's like I don't want people to come to our house to find out that I have a mentally sick cousin in the home, so at times, I just have to ignore or refuse friends who want to visit me in the house I just give excuses. I am afraid of the stigma attached to mental illness and how society extends the stigma to other family members and even mental health professionals. They intentionally make hurting statements to the effect that you the caregiver is also sick in the head.

4.2.6 Beliefs about the causes of schizophrenia

Caregivers revealed to the author their beliefs about the causes of schizophrenia. They have a belief that schizophrenia is a spiritual illness caused by some demonic supernatural powers unseen by human beings who select an individual in a chosen family and afflict that individual with a chronic disease which is always not curable like HIV/AIDS, cancers and mental illness of all kind to torment the affected person and his

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family. Caregivers also identified ancestral curses as one of the causes of schizophrenia. Majority of the caregivers have the belief that when an individual offends the ancestors dead and gone, they either summon you to answer the charges and in that case, you die. Or, they punish you in the physical by giving you a disgraceful disease condition like schizophrenia. Participants also stated that they belief satan is a strong opponent of God, anytime it sees God's favor on an individual, it becomes envious and afflict that person with a disgraceful disease condition like mental illness. The belief that schizophrenia is a spiritual disease was evidenced in statements made by these participants.

Madam Kukua is a 38 year old seamstress. She is single and has been a caregiver to her aunt for 15 years. She explained her belief that schizophrenia is a spiritual disease:

> I belief schizophrenia is a spiritual illness because since I started going for prayers with my aunt alongside the medications, I have seen much improvement than before. Satan is afraid of prayer so prayer should not be ruled out in the treatment of schizophrenia.

Nii is a 24 year old sales university student. He has been a caregiver to his grandmother for 5 years. He said:

> I believe this is a spiritual illness caused by evil forces in the spiritual realm. So I have taken him to several churches and prayer camps for deliverance because I feel the medications are not enough to handle the signs and symptom the patient shows and so spiritual intervention is needed.

Twenty three year old Ocancy has been a caregiver to his mother for the past two years. He also believed schizophrenia has a spiritual part. He stated

> My aunt is a prophetess. She told me the disease is a spiritual disease and I belief it is true. She has been given me spiritual directions in my care giving. I anoint her with anointing oil every night and also pray over her medications with anointing water otherwise, the spirits can weaken the potency of the medication

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Caregivers have the belief that schizophrenia is caused by satan and so needed supernatural healing. Caregivers said schizophrenia is a satanic disease brought by the devil himself to oppose God‘s blessing on an identified individual. They explained that satan is a strong opponent of God so anytime it sees God's favor on an individual, it becomes envious and afflict that person with a disgraceful disease condition like mental illness. Others also belief is a way of satan to deny God‘s children from entering into paradise.

Madam Naa is 68 years old. She belongs to the Jehovah‘s Witness set. She has been a caregiver to her daughter for the past 30 years. She stated why her belief on schizophrenia is a satanic disease:

> I believe is a sickness caused by satan to deny children of Jehovah from entering into paradise. I believe is a spiritual Warfare we have as children of Jehovah if you don‘t understand this, you panic but as a witness of Jehovah I will overcome. Satanic diseases like mental illness need Jehovah‘s intervention.

Okaine is 46 years; his father is a retired pastor and has 25 years of caring experience:

> I believe is a satanic disease. Satan has a hand in it to worry God‘s children so payer is the key. Our elder brother is a pastor so I know is a spiritual attack on our family. My father was also a church leader so the family is always praying because we know what the devil is capable of doing.

Ancestral curses was also identified by the researcher as one of participants’ believe as the cause of schizophrenia. This is the belief caregivers have about the causes of schizophrenia that it is caused by ancestral curses. Most caregivers interviewed held the believe that because they have refused to serve deities in their traditional homes, they are tormenting them. they believe they will have to take the patients through elaborative treatment modalities at shrines for spiritual exhortations by a priest or priestess of

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those shrines who caregivers belief are mandated by the ancestors to intervene on behave of the living for those spiritual duties or herbal.

Madam Dzifa is a 53 year old ward assistant caring for her son for the past 8 years. She has been separated from her husband because she refused to follow her husband to the shrine for spiritual exortions for the patient. She said:

> I believe is a spiritual illness brought by ancestral curses from the gods from my husband‘s hometown because when my son got lost the first time, he said he saw the priestess of the deity in his father‘s hometown with his dead paternal grandmother outside of the house beckoning him to come with them and he was never able to locate the house again. He knows the priestess because his father has been taken him there to consult ancestral spirits to heal him. I learned my father in law has offended the ancestor and the punishment is what my son is suffering now their gods want to sacrifice my son.

Madam Araba, a 54 year old mother of four caring for her son for the past 11 years had this to say:

> I believe this disease is a spiritual and evil illness given spiritually by family ancestors and family witches who see the future of children who will be successful in the future and waste their life because aunty (referring to the researcher), I believe my elder sister has a hand in my son‘s illness because she insults me with my son‘s sickness. She is happy my son is sick and I have made her aware she is responsible for my son‘s condition.

4.2.7 Other outlets of treatment

The experiences of caregivers were also explored to determine the extent to which caregivers use other outlets of treatment for their family member with schizophrenia. Participants stated other outlets of treatment to be prayer camps and herbal treatment. Caregivers interviewed said prayer camps are the first point of call when an individual start showing signs of mental illness. At prayer camps, a prophet or prophetess

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prophesy the cause of schizophrenia to be spiritual and give prophesy as to how the spiritual treatment modalities should be. Most often than not, the caregiver is tasked to fast and pray on behave of the patient. Other times too, the patient is made to undergo spiritual cleansing by praying and fasting. Most pastors operating these prayer camps anoint the patients with special oils with the belief that it will bring out the evil spirit tormenting the patient. Caregivers also mentioned herbal treatments as one of the treatment outlets they source for their family member with schizophrenia. Caregivers profess that combination of herbal treatment and Christian prayer works better. Caregivers confessed that it is only when these two treatment outlets fail that they start going to the hospital for orthodox treatment.

This was evident in a statement made by Mr. Nkansah, a fifty four year old driver, and a father of five caring for his wife for the past three months post discharge. He stated:

> I believe is a spiritual illness so prayer is the best treatment to cure this illness. I have been sending her to Abo Offie‘s prayer camp for spiritual cleansing and anointing to drive the evil out of her. I do send her for prayer before coming for review at the hospital. I know this is a spiritual attack on my wife‘s person so it is only prayer and fasting that can heal her. I bring her to the hospital because of what people will say but if I have my own way, I will choose prayer as the best treatment outlet for schizophrenic patients.

Twenty six year old Miss Sena, a polytechnic graduate and a sales manageress

> I believe is a spiritual illness, so I have been to churches and prayer camps because I feel the medications are not enough to handle the signs and symptom the patient shows and so spiritual intervention is needed. I visit some of the prayer camps here in Accra, some in the Volta region, some in the central region and also do visit herbalist very often

4.2.8 Caregiver needs

This section focuses on the needs expressed by caregivers. They explained their needs as those things that can be done to lessen the burden they face in their care giving roles.

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Various forms of needs were expressed by caregivers such family support, health education from health care professionals, home visits by community psychiatric nurses, the need for them to be educated on the signs and symptoms of relapse, diagnosis of the patient and the need for extra hands to continue care in their absence as caregivers. Caregivers interviewed talked about the neglect of the patient by extended family members. They stated that most family members do not want to associate with the patients and the caregivers. Most caregivers said they have no support from other members of their family. In some cases, caregivers reported of neglect and poor financial remittances from their working children. Seventy four year old retired electrical engineer, Mr. Fiadzo has been a caregiver to his son for 19 years. He expressed:

> There is nothing like support from any external family member. My extended family members think I have money because my children are in America. I have no help from the extended family. It is my children who were helping but even now, they say they are fed up with the patient so there is no remittance from anywhere.

Madam Dzifa is a 53 year old ward assistant who is facing separation from her husband because of her care giving role. She stated:

> No support from anywhere. Not even the patient‘s own father. Everything is on me

Seventy year old Madam Adoma said:

> External family support, from whom? They even insult me that I have used my son‘s mind for money rituals so who will support me. As for my extended family, is all about insults, insinuations and quarrels if this is what we call support, then I have some.

Findings of the study again revealed that health care providers do not educate caregiver on the signs and symptoms of relapse and on schizophrenia as a mental condition. Caregivers identified health education as one of their needs. They expressed that, they are

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always taken by surprise on patients relapse because they have no education on the signs and symptoms of relapse.

Twenty four year old Nii is a student and a caregiver to his grandmother. He typified this view in the following statement:

> I think education for us the informal caregivers on this type of mental illness plaguing our families will do the trick. It will even relieve the burden on the health professionals because it will even reduce the rate of relapse so that the decongestion of the limited psychiatric hospitals that is being propagated by the psychiatric people can be realized.

Madam Naa is a retired receptionist and a divorcee. She has been a caregiver to her daughter for thirty years but has never been educated on the signs and symptoms of relapse nor her daughter‘s diagnosis.

> I know Gifty has a mental problem but I don‘t know the type that she has. I never knew there were different types of mental illness. I have cared for her for over 30 years but I have never been told what her diagnosis was. Also, no health professional has ever educated me on the signs and symptoms of relapse. My knowledge on the signs of relapse is because of the years of care it has come through experience but not an official education from health care professionals.

Caregivers said they will be happy if they can have health care professionals especially community psychiatric nurses visiting them at home to see what they do with the patient at home and if possible, suggest caring modalities for them as informal caregivers. Madam Serwaa is a tax administrator, married with two children. She has cared for her aunt for 20 years. She shared her care giving experience with the author this way:

> If the nurses can visit us at home to see what we go through with the patients it will be best. So that when we come and say we want admission for the patient, they will understand it. They are paid to do this work we are doing at home. I learnt some group of nurses are supposed to come home to see the patient and educate us informal caregiver on the patients’ daily living and the signs of relapse but they don‘t come. We need them to visit and educate us.

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Mr. Okaine, forty six year old electrical engineer has been a caregiver to his elder brother who was one time a medical student also explained his need for home visit. He said:

> At first, the nurses were visiting us at home to educate me on how to care for the patient, the importance of review, signs and symptoms of relapse and many other things. At a point, I could even call them when need be but now they don't come so if they can start that it will help we the informal caregivers. Also if there can be reduction for the cost of medications it will help because some of us are pensioners and live on meager incomes so the government should assist.

Findings revealed that caregivers need extra hands to care for different reasons. Some needed extra hands to be able to concentrate on their work, some needed a male figure to help, others also needed extra hands so that in the event of death, there will be somebody to continue care. Older participants expressed their fear on whom to continue care in the event of their death. Seventy year old Madam Adoma typified the situation as follows:

> I need a helper, someone I can trust to continue care even when I am not alive though I believe my son will get better before I die. I need financial help too because everything is money be it money for reviews or money to travel for spiritual healing one need a helping hand.

For younger caregivers, extra hands are needed to help them concentrate in their education or on their work. Twenty three year old student, Master Nii explained this as follows:

> I need an elderly woman to assist me to care for my grandmother. Though my uncle assist financially, the other aspects of care is left for I alone. When is review time, I am called from school to send her for review. When the patient relapses I am called to send her for emergency treatment. This role is affecting me academically. I need someone to take charge when I am out of the house

Findings of this study again revealed that most caregivers did not know the diagnosis of the patients they were caring for. Caregivers did not think it was important to know the

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diagnosis. Some caregivers had the understanding that mental illness had just one diagnosis for all its manifestations. Most participants were surprise to know mental conditions have many different diagnoses as medical conditions.

Fifty four year old Madam Araba, has been a caregiver to her son who was one time a student at the Teacher‘s Training College.

> I don‘t know my son‘s diagnosis but I know he has mental illness and that is fine with me. After all whether you know the diagnosis or not, it will not change anything about the condition. Those who need the diagnosis to treat him know and understand so what again do I need it for.

Thirty eight year old school dropout, now a seamstress, Madam Kukua, who has been a caregiver to her aunt for fifteen years stated:

> I know the patient has a mental problem but I didn‘t know there are different types of mental illness maybe her sister has been told because the sister is a doctor. But for me, all I know is that I am caring for someone with a mental condition. I have never been told of any type may be they didn‘t think it was important to tell me

4.2.9 Attitudes of health care professionals

Caregivers expressed positive and negative attitudes they have observed with health care professionals at the Pantang psychiatric hospital the setting for the present study. Those who had positive things to say about them said they are impartial and treat both patient and caregivers with respect and dignity. They said the health staffs were prompt to emergencies especially when a patient is aggressive. This positive perception about health professionals were typified in the following two expressions. Master Ocancy a twenty three year old senior high school student, caring for his mother for the past two years stated:

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> I think they are very nice people and they have a lot of patience because when we come to the hospital, they receive us well and look for our folder and send us to the doctor. The doctor will also be patient with us ask about everything that has happened in the house since the last review before giving us prescriptions for our medications. So I think they are doing well. No nurse comes to the house to visit her though.

Nii, a twenty four year old university student who has been a caregiver to his grandmother for the past five years also remarked and said:

> Well since I came here I have not received any kind of disrespect from any worker here as compare to the general hospitals so I think they are good. The work they do here is a difficult one so the way they are able to attend to patients and their caregivers with such respect is something I appreciate.

In sharp contrast, others feel the health staff discriminate specially when patient relapses and needs admission they think some of the health care professionals are corrupt because they refuse admissions for relapse cases but when you are able to bribe your way through or if you know someone who work at the facility, you are able to get admission for the patient. They believe those were some of the reasons other families dump their mentally ill patients at the psychiatric hospitals and never return for them.

Madam Serwaa was not happy with the attitudes of staff and depicted that with the following remarks:

> Honestly I feel bad about the way the health workers treat us when we come to ask for admission, because when you check our history we don‘t come to dump her here, and it is only when she is being violent in the house that we bring her for admission but when we come to ask for admission they tell us there is no space on the ward but when we bring someone who works here to talk to them on our behalf then they will accept her into the ward especially when you send her to the VIP ward then they will start treating you well. This gives me the perception that there is some sort of discrimination in the services they provide here and I think it is that attitude that makes people dump their relatives here.

Another caregiver, Mr. Okaine also made the following remarks about the negative attitudes of health providers:

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> At times the nurses think we neglect the patients and that is the reason why the patients relapse but it‘s not always the case. It is when you are close to them that you will know how difficult it is but sometimes we understand them because of the number of patients they have to take care of, they get tired and displace their anger on those who default for review.

4.2.10 Obligation to care

Findings of this study revealed that, caregivers feel it is their duty to care no matter what their own health status might be because of their relationship to the patient. Some caregivers believe that they are obligated to care because the patient is a blood relation so is for better or for worse. Some caregivers were of the view that if the sick person had brought some fortune in the form of riches, they would have enjoyed it so if it is sickness, they have to accept and give care. . Other participants also believe there will be nobody to care if they don‘t. Some caregivers also have the fear that patient may be harmed by others who may not understand their behavior and so have accepted the caring responsibilities.

Sixty eight year old Naa caring for her daughter for the past thirty years talked about her obligation to care as follows:

> Everybody in my family is thinking about themselves so being the mother of the patient, I cannot reject her she is my blood. She is my property so whether good or bad, I have no option except to care and that is what I am obliged to do.

Fifty three year old Dzifa also emphasized her obligation to care as follows:

> I have to give care to my son no matter how difficult that will be because I gave birth to him, he has my blood. If it were success, I would have enjoyed it. Now that is sickness, I have no option but to give care.

Caregivers interviewed told the author that there is no one to care if they don’t give care. Participants explained that other family members are not ready to sacrifice their time,

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work and comfort to take up the responsibility as a caregiver knowing the burdens that comes along with it. Participants again told the author that other family members feel the condition is chronic and the role as a primary caregiver is stigmatized by society. So other family members are not ready to play that close role. Most caregivers accept to care out of affection for their immediate family member as complied in the following statement from 74 year old retired electrical engineer:

> I have no option otherwise I will reject this patient. no one will care if I don't I told you his siblings in America are all fed up with him because this is a strong energetic young man who thinks he is not sick and so will not take his medications he spends monies that comes to him unnecessarily. He doesn't accept that he is sick. In fact if I have any option, but for the fear the he may be harmed by others, I would have let him be on the street where others are. I am seventy four years I have not much strength. I am just being conscious of my health otherwise I would have had hypertension and die.

Fifty four year old Araba, emphasized her obligation to care as follows:

> I can't send my son away. I am obliged to take care of him because nobody in my family and that of his father's family wants to associate with the patient's condition. This condition cannot be handled by anybody because you have to care with love so as a mother, no matter how difficult it is, I still have to give him the care he needs because nobody is ready to take over the care giving role. I just pray that he gets well before I die otherwise it will be difficult for him.

The researcher in her analysis realised that most caregivers took up the responsibility to care because they were afraid the patient can harm people resulting from hallucinations or be harmed by others who may not understand their behaviors. They stated that some of the patients can also be aggressive physically and verbally and individuals who may not know they are mental patients may take offence and harm them as a result. Fifty four year old Mr. Nkansah caring for his wife post discharge for the past three months stated:

> I am afraid somebody can harm the patient because she makes wild spiritual allegation against passersby, calling them witches and wizards. She also gives –prophesies to individuals who come to our house and some of them take offence at her statements. Maybe if I

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> were not available to explain her condition, I can even end up in court with her.

Thirty eight year old Madam Kukua, single and a seamstress. Kukua has been a caregiver to her aunt for 15 years. She stated:

> I am always careful not to allow the patient alone to go out. If she must go, then she must go with me because I am afraid she can be knocked down by a moving vehicle. Other times too, I entertain the fear that she can relapse and become aggressive physically or verbally and in that situation harm people or be harmed by others who may not know she has a mental condition.

4.3 Caregivers' unspoken words

This involves the various actions, reactions, and mannerisms exhibited by participants whilst expressing their sentiments about their experiences as caregivers for individuals with schizophrenia.

4.3.1 Mannerisms

Words like: "hmm'', ''eh'', ''oh'', ''err'', appeared in participants' speeches. These were indications that some of them were emotionally shattered and downhearted. With some of them, it was evident from these unspoken words that there is nothing they could do; than to just try and cope with the difficulties in care giving.

4.3.2 Behavioral reactions

Some participants had tear-filled eyes, but tried hard to avoid shedding tears. However, some could not control themselves than to shed tears. One widowed caregiver wept bitterly throughout the interview whilst expressing her sentiments. Some participants also shook their heads and threw their hands as signs of despair.

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4.3.3 Perception about interviewees

Most participants were reluctant in bringing out their experiences during the interview sessions due to the fear that information gathered from the interview may be published in the media. However, some were willing to participate and showed keen interest in the interview. The researcher also observed that some of these participants were so much worried about their family members' psychiatric condition that, they thought participation in the interview would help relieve them of the burden they were going through.

Some participants saw the interview as a bother and intrusion into their private affairs. Participants who had knowledge about research were eager and ready to be involved in the research. Some were also relaxed and felt comfortable probably because they knew as a psychiatric nurse; the researcher could help relieve them of their problems with informal care giving.

Notwithstanding the few problems encountered, the interview sessions were very successful and therefore the researcher was able to achieve the objective of the research.

Summary

In conclusion, this chapter has presented a detailed description of the caregivers' experiences on care giving for their family member with schizophrenia leading to the source of discussion in the next chapter

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CHAPTER FIVE

DISCUSSION

5.0 Introduction

The previous chapter analyzed data the researcher gathered from her participants. In this chapter, the themes and sub themes found in caregivers' report of their experiences provided the basis for discussion. The various themes were examined in the light of the available literature to determine areas of congruence or otherwise. Thus, the findings on the experiences of caregivers of individuals with schizophrenia were used to confirm or build on ideas from the literature.

5.1 Caregiver burden

Different forms of burden were identified in the analysis which highlights major problems families that have a member with schizophrenia go through. Caregiver burdens identified included: psychological and economic burdens, and impact of caring on caregivers' health.

The findings of this study revealed that caregivers have deep seated sadness because they find it difficult to accept why their family member should be suffering from schizophrenia. Caregivers therefore go through stress to cope with patients' bizarre behaviors'. They also expressed the fear of who would take over care giving in the event of death. Caregivers also emphasized the financial hardships they go through as a result of the resources required to finance patient's treatment and also take care of other family responsibilities as most caregivers interviewed, doubled as bread winners for their families. Care giving has also impacted negatively on participants' health as most participants confirmed having developed hypertension from the stress of giving care to

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a schizophrenic patient. Others had become disorientated in one form or the other as was the case of the caregiver who had road traffic accident as a result of excessive thinking. These burdens as revealed by caregivers support the report by Dorian et al., (2008) that caregivers' encounter a wide range of stressors for themselves and these include feelings of sadness or depression, and long years for reviews. A similar view was expressed by Pinquart, and Sörensen, (2007) whose study revealed that majority of caregivers studied had some form of depressive and anxiety symptoms. They therefore concluded that a high percentage of caregivers often experience mixed emotional disorders (anxiety and / or depression).

In consistent with the findings of this study, Chadda et al., (2007); Creado et al., (2006); Scazufca and Kuipers (1999), have also reported that caregivers encounter a lot of negative reactions such as feelings of intense grief and forgetting about reality. Their study revealed that the idea of death was always in participants' mind, and divine interventions were always expected by most participants. Sreeja, Sandhya, Rakesh, and Singh (2009), agrees that care giving for schizophrenic patients places a heavy burden on individuals and their family caregivers, as well as potentially large demands on the healthcare system.

Most participants interviewed revealed the negative impact of care giving on their health. For instance, one participant indicated becoming hypertensive because of patients' aggressive and insulting behaviours. Findings tallies with the study done by Pinquart and Sörensen (2007) which reviewed 176 studies on correlates of caregiver physical health and reported that greater caregiver burden and more severe depressive symptoms were related to worse physical health. Similarly, Chien et al. (2007) studied the perceived

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burden among Chinese family caregivers of people with schizophrenia and found that family burden was significantly and negatively correlated with health status. The difficulties caregivers' narrated also tallies with World Health Organization's observation that although the incidence of schizophrenia is low (3 per 10,000), its prevalence is high due to the chronicity of the illness hence the burden in care giving (World Health Organization, 2010).

5.2 Impact of care giving on social life

Among the troubling social impact of participants was the impact of care giving on marriage and intimate relationships. The impact of care giving on caregiver's social lives consisted of how their care giving roles affect their intimate relationships and marriages, due to consistent observations needed to handle schizophrenic patients' unpredictable tantrums and prolong recovery. Compounding this social alienation is the impact of care giving on caregivers' work out put. Lateness to work, frequent permissions to attend to patients' health needs in relapse situations, coupled with absenteeism to work, which results in numerous warning letters from their managers. Other social encounters by caregivers include social isolation, loneliness, and Stigma. Caregivers indicated they went through periods of loneliness and intentional social isolation daily knowing that they are stigmatized socially because they have a family member with mental illness. Participants' encounters were consistent with the study by Frey (2009), which revealed that the prevalence of divorce was higher in male caregivers. However, unlike the current research, the study was a quantitative study. The study did not also state the prevalence of divorce amongst female caregivers. It did not also acknowledge single caregivers. One of the commonest social experiences of participants was the inability to attend social functions such as funerals, parties and out-

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dooring ceremonies. Participants attributed these to the fact that these social functions conflict with their care giving roles hence their inability to socialize. Caregivers intentionally isolate themselves socially to avoid embarrassment from patients' behaviors. Fujino and Okamur (2009), reported in their study on care giving and socialization that care giving for chronic conditions results in changes in caregivers' ability to socialize. The findings of the current study is also consistent with that of Larsen and Lubkin (2006) who found out in their study that interference with social and recreational activities were the stressors unique to caregivers of schizophrenic patients.

Similarly, Huang, Sun, Yen and Fu (2007) also found out in their study that there was a feeling of confinement and social isolation among caregivers of schizophrenia because of their inability to socialize.

Participants also stated that stigma was in a very subtle form from health staff, extended family members and friends. A similar view was expressed in an unpublished qualitative work by Morny (2003) in Ghana on the effects of the stigma experiences of chronic psychiatric patients at the Pantang psychiatric hospital, the same setting for this present study. It was found that the mentally ill and their caregivers are discriminated and stigmatized by healthcare providers, relatives, employers, coworkers, colleagues and church members in such manner as disregarding their opinions, relieving them from their jobs and discriminating against them where ever it is known that they were once a mental patient or that they are caregivers of a mental patient. Caregivers also mentioned stigma as a problem impacting negatively on their social lives and a reason for avoiding social function. This is also consistent with Chang and Morny (2003) who found that family caregivers have to cope with the impact of stigma of their relatives' mental

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illnesses. A study of Hong Kong Chinese families found that much of the burden was related to stigma and lack of mental health and rehabilitation services. The consequences of care included social isolation of the families and financial difficulties. Subjective burden resulting from social stigma included frustration, anxiety, low self-esteem, and helplessness.

Among the concerns of participants in this study were the negative impacts of care giving on their work output. All participants reported that their productivity levels had significantly been affected. They attributed this to the encroachment of their care giving roles on their time as well as productive working hours. Those who were self employed expressed that due to the time spent on the patient, they were unable to do meaningful business transactions as well as good supervision and this made them unproductive. One participant reported that he had to stop his business and stay with his wife (the patient) at home for fear of patient being harmed by others. These findings are in agreement with work done by Mwinituo and Mill (2006) who found that relentless physical care giving among blood relations of AIDS patients who reported of exhaustion, anxiety and depression, resulted in their loss of jobs and their self employment activities. It also agrees with Foldemo et al., (2005); Gutiérrez-Maldonado (2005); Hanzawa, et al., (2008) whose studies revealed that among caregivers experience of mental and physical fatigue was functional capacity. They further unveiled that care giving had a great effect on caregivers in terms of their performance and lack of time as well as lack of peace in their daily lives. The researchers however, did not explain what they meant by performance but it can be linked to job performance and hence productivity in the current research.

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5.3 Beliefs about the causes of schizophrenia and other outlets of treatment

The world view of Ghanaians on beliefs of the causes of mental illness being a spiritual illness, manifested in all the participants interviewed. Findings revealed that participants believe that schizophrenia is a spiritual disease caused by witches and wizards in the family who are jealous of one's success in life. They supported their stand with the fact that when they sought spiritual interventions from 'men of God', there was much improvement than when they were only relying on orthodox medications. Some participants also said they believe the condition is caused by ancestors dead and gone who punish the living who offends them with mental illness. As one caregiver recounted her son (the patient) got lost and when found told her that he saw his paternal grandparents who were dead and a priestess who is in charge of patient's father's deity in their hometown who he saw came to the house and beckoned him to follow them and took him away from the house. This caregiver said is because she has refused to serve the gods with the husband so that is her punishment for not serving the gods. Other caregivers said schizophrenia is a satanic disease so whoever refuses to serve satan can be afflicted with mental illness. To buttress this point, Assimeng (2010) in his book religion and social change in west Africa stated _the field of inexplicable in day-to-day human experience, is very wide.

5.4 Other outlets of treatment

The experiences of caregivers were also explored to determine the extent to which caregivers use other outlets of treatment for their family member with schizophrenia. Participants stated other outlets of treatment to be prayer camps and herbal treatment. Caregivers interviewed said prayer camps are the first point of call when an individual start showing signs of mental illness. At prayer camps, a prophet or prophetess,

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prophesy the cause of schizophrenia to be spiritual and give prophesy as to how the spiritual treatment modalities should be. Most often than not, the caregiver is tasked to fast and pray on behave of the patient. Other times too, the patient is made to undergo spiritual cleansing by praying and fasting. Most pastors operating these prayer camps anoint the patients with special oils with the belief that it will bring out the evil spirit tormenting the patient. Caregivers also mentioned herbal treatments as one of the treatment outlets they source for their family member with schizophrenia. Caregivers profess that combination of herbal treatment and Christian prayer works better. Caregivers confessed that it is only when these two treatment outlets fail that they start going to the hospital for orthodox treatment.

These findings are in agreement with work done by Assimeng (2010 p 54, 58, 59) who found that most often, an illness, especially if its cause could not be directly observed, was ascribed to supernatural powers as humans applied subjective notions about their environment to ailments whose origin and prognosis were beyond their comprehension.

Assimeng (2010), states that the creator of the universe gives good luck and ill luck to the living as rewards for good service or punishment for evil deeds. Evidence also indicates that the less social support a career has, the more often spiritual help is used as a coping strategy (Magliano et al. 1998)

5.5 Caregiver needs

Various forms of needs were expressed by caregivers such as family support, health education from health care professionals, home visits by community psychiatric nurses, the need for them to be educated on the signs and symptoms of relapse, diagnosis of the

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patient and the need for extra hands to continue care in their absence as caregivers. Caregivers interviewed talked about the neglect of the patient by extended family members. They stated that most family members do not want to associate with the patients and the caregivers. Most caregivers said they have no support from other members of their family. In some cases, caregivers reported of neglect and poor financial remittances from their working children. This agrees with a qualitative study on the Needs of Caregivers by Jagannathan *et al* (2011) that family members of a patient with chronic schizophrenia have multiple needs. The major concerns and support needs of individuals who assume this stressful role include obtaining support, reducing risks to their own well-being, and promoting the well-being of the mentally ill.

These revelations are consistent with the findings by Underwood (2000); and Gallant (2003) that support from family members and friends may be valued to facilitate the emotional and tangible support. In addition, Chen and Greenberg (2004) said, mental health professionals can be a source of formal support to family members by educating caregivers on patient‘s condition. In their work Nemade et al. (2007) suggested professional support, in particular, practical advice on managing disruptive behaviors to reduced objective burden.

5.6 Attitudes of health professionals

Participants views on the attitude of health professionals, was an experience of either a positive or negative attitude. Caregivers who spoke well about the attitude of health staff stated that when they look at the limited resources and neglect from central government to psychiatric hospitals and the nature of patient that are cared for in these hospitals, they think the staff is doing their best with the meager resource available to them. Some said that, they are commended anytime they accompany the patient for review. One said

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he was amazed with the promptness with which the staff responded and handled his wife's aggressive behavior when he brought her for admission. Other caregivers also saw more of staff's negative attitude and alleged partiality in terms of getting admission for relapsed patients. To buttress this point, Roberts, Asare, Mogan, Adjase and Osei (2013), in their study on mental health system in Ghana revealed that limited beds at the three main psychiatric hospitals, and the delays associated with feeding grants from central government to psychiatric hospitals, has resulted in over sixty percent cut down in patients admissions. They resolved that as a result of the limited admissions beds, many more patients are refused admissions

5.7 Obligation to care

Findings of this study revealed that, caregivers feel it is their duty to care no matter what their own health status might be because of their relationship to the patient. Some caregivers believe that they are obligated to care because the patient is a blood relation so is for better or for worse. Some caregivers were of the view that if the sick person had brought some fortune in the form of riches, they would have enjoyed it so if it is sickness, they have to accept and give care. Other participants also believe there will be nobody to care if they not there to care. Some caregivers also have the fear that patient may be harmed by others who may not understand their behaviour and so have accepted the caring responsibilities. This finding could be linked to Aggarwal, Avasthi, Kumar, and Grover's, (2011) finding that caregivers of heamodialysis patients employ a wide range of ways in managing the quality of lives of their family member needing dialysis because of the tide of blood. Thus, the love and support from family members and significant others help haemodialysis patients in managing the quality of their lives and therefore helps in their survival.

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CHAPTER SIX

SUMMARY AND CONCLUSION, IMPLICATIONS TO NURSING PRACTICE, POLICY AND RESEARCH, LIMITATIONS OF THE STUDY AND RECOMMENDATIONS

This chapter, presents a summary of the entire research has been given and a conclusion drawn. Findings of the study provide the background method for nursing practice, policy and research. The limitations encountered during the study have also been outlined and due recommendations suggested.

6.1 Summary and Conclusion

The World Health Organization estimates that globally about 29 million people have schizophrenia. Although its incidence is low (3 per 10,000), its prevalence is high due to the chronicity of this illness.

Available statistics in Ghana shows that over two million individuals are diagnosed as suffering from moderate to severe mental illnesses. But only two percent of these numbers have access to psychiatric treatment from the three psychiatric hospitals and other psychiatric units in our general hospitals. The over ninety eight percent of these patients are cared for by their family members. again, available statistics from the Pantang hospital, the setting for the present study, identified schizophrenia as the leading condition reported and diagnosed since 2011 to date.

This study set out to find the experiences of caregiver of schizophrenia in the Accra Metropolis, and the main purpose was to document the experiences of caregivers of

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individuals with schizophrenia in order to inform new strategies to support Ghanaian family members.

The study was qualitative in nature and it was conducted at the Pantang psychiatric Hospital in Accra, Ghana. Pantang was chosen for this research because of the closeness to the researcher, and the fact that it handles a larger population of schizophrenic review cases.

Twelve (12) caregivers (between the ages of 23 and 74) who accompany their schizophrenic family member for reviews were identified and interviewed using an interview guide which reflected the objectives of the study. The interviews covered the four objectives set by the researcher which is to describe the experiences of the caregivers for their schizophrenic relatives, to explain family caregivers‘ perceptions of what is or could be helpful in supporting their efforts to care for their schizophrenic relative, to determine family caregivers‘ perceptions of the impact of caring on the caregivers‘ health, and to describe caregivers‘ perceptions of care burden, needs and the degree of social support available to caregivers. The interviews were audio taped and transcribed verbatim.

Through content analysis, seven major themes emerged, and these include, caregiver burden, impact of care giving on caregivers’ social life, caregivers’ believe about the causes of schizophrenia, outlets of treatment, caregiver needs, attitudes of healthcare professionals, and obligation to care. The above findings could be grouped under one objective or the other. For example a finding like caregiver burden can be listed under objective four; caregiver need can also be listed under objective four. However, beliefs

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about the causes of schizophrenia and outlets treatment can be grouped under objective one.

Acknowledging these care giving experiences of caregivers may help clinicians especially nurses who work at the psychiatric hospitals better understand informal caregivers in order to provide the needed professional support which will help caregivers patients behavior and what to do when patient relapses. The study can therefore be said to be very relevant and also benefit mental health nursing practice. The study also indicates that further research is required in the area of coping strategies and quality of life of caregivers of schizophrenic patients in the Ghanaian context.

6.2 Implications to Nursing Practice, Policy and Research

The issue of informal care giving for schizophrenic patients comes with a wide variety of implications in nursing. Psychiatric nurses caring for psychiatric patients, should not only concentrate on the psycho biomedical aspect of the patient, and neglect the caregivers who are responsible for the patient in the home. However needs assessment of both client and family, health education to caregivers caring for the mentally sick, follow up visits, individual and family therapy sections and counseling for patient and families, are said to be part of the nurses‘ role in caring.

Informal caregiver assessments may also play an important role in knowing the needs and understanding the informal caregiver so that their perspectives on these matters can be approached within the nurse- family- relationship paradigm. In order for caregivers to attain optimal quality of life in their care giving roles, it is essential to help them handle challenges they encounter.

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It is therefore very important to know the challenges and experiences of non professional caregivers; to help them successfully negotiate the difficult transitions that come with care giving. The nurse can accomplish this by providing comfort and safety to patients, encouraging patients to express concerns and feeling and embarking on patient education.

The ministry of health and the management of the Pantang Hospital should make collaborative efforts at ensuring that health care professionals working at the psychiatric outpatient department receive constant training through workshops and in-service training. Seminars and conferences should be done more often to update on current practicing trends to help deliver quality care to both the mentally ill and his family.

The management of the Pantang Hospital should intensify efforts at acquiring the needed human resources for the various specialty areas in mental health care. Community psychiatric nurses should be officially trained for proper follow up visits. Health staff should intensify education of patient and family caregivers. Government should employ more psychiatric social workers to help assess and identify the social and economic issues caregivers have, more psychologist be admitted to handle the psychological issues associated with informal care giving, occupational therapist to help give skills to patient on admission so that after discharge they can be well integrated back to society

The government, in collaboration with the ministry of health and the Pantang

Psychiatric Hospital as part of their policies, should equip the only two psychiatric institutions in the country to officially train community psychiatric nurses and occupational therapists for the psychiatric institutions. The ministry of health should

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recognize the contributions of the informal caregiver as part of the mental health care hierarchy and support them financially or include them in the Livelihood Empowerment Programme (LEP) to also have financial support from central government. Future researches on informal care giving should also assess the deinstitutionalization policy of government and its effect on patients and informal caregivers' quality of life

6.3 Limitations of the study

The study was done only at the Pantang psychiatric hospital and can therefore not be generalized to the other psychiatric hospitals in Ghana. Formal caregivers at the hospital were not made part of the study although the study touched on some aspects of their services and could have made available important information about their services to informal caregivers. Also due to the self report of the study, a recall bias is possible.

Some participants, though assured of confidentiality, were still couscous of coming out with their experience. Some interviews were longer than expected because some participants did not want to be audio taped hence, the researcher had to write pages for an interview.

Personal experience: The initial stage of the data collection was rough due to difficulty in recruiting participants. Travelling to the field did not yield positively most of the time because participants kept changing dates and time for interviews. Another difficulty that emerged was limited financial resources which affected the research process because the researcher used commercial vehicle for her travel on major roads to have interviews done during the pilot study. The researcher was subjected to the rains and the scorching sun. There were several occasions where she had no choice but to chatter taxi to facilitate movement in spite of the limited resources.

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6.4 Recommendations

Based on the research findings the following recommendations are made:

- Education and counseling centers should be available in the communities for informal caregivers to access.
- Other areas in psychiatry like community psychiatric nursing and psychiatric social work should be strengthened to enhance follow up visits and handle social problems faced by patients and informal caregivers
- The National Health Insurance Authority should include psychiatric treatment in their vulnerable list for free access to health care to reduce the financial burden on informal caregivers.
- Government should recognize informal care givers and include them in the Livelihood Empowerment Programme to lessen their financial burden
- The two psychiatric institutions should be accredited to train post basic mental health nursing in community psychiatric nursing.
- Government should establish psychiatric training school and a psychiatric hospital in the middle and northern sectors of the country to reduce transportation cost on families living with a member with mental illness.
- There should be recognition, education, and research on other outlets of treatment for psychiatric conditions

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APPENDICES

APPENDIX A: INTRODUCTORY LETTER

Pantang Psychiatric Hospital

10th January 2013

To: In charge, OPD, Social Welfare, etc.

Dear Sir/Madam,

Letter of Introduction

RE: Florence Animwaa

The above is an M.Phil student of the School of Nursing, College of Health Sciences, University of Ghana undertaking a research entitled: *"Experiences of Caregivers of Individuals with Schizophrenia in the Accra Metropolis"*.

She has chosen Pantang Hospital as the focus of her study with emphasis on informal caregivers of individuals with schizophrenia who come for regular review. Ethical clearance has been acquired from the Ethics Committee of Pantang Psychiatric Hospital.

We will be very grateful if you could let her have access to the informal caregivers for her data collection. The location for the interviews will be negotiated between the researcher and the participants. Please ensure that the participants sign or thumbprint the consent forms.

Attached are copies of her application and ethical clearance from her institution.

Thanks for your cooperation.

Yours sincerely,

Dr. Benedictus Wozuame

Chairman, Ethics Committee.

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APPENDIX B: ETHICAL CLEARANCE

NOGUCHI MEMORIAL INSTITUTE FOR MEDICAL RESEARCH
Established 1979
A Constituent of the College of Health Sciences
University of Ghana

INSTITUTIONAL REVIEW BOARD

Phone: +233-302-916438 (Direct)
+233-289-522574
Fax: +233-302-502182/513202
E-mail: nirb@noguchi.mimcom.org
Telex No: 2556 UGL GH

Post Office Box LG 581
Legon, Accra
Ghana

My Ref. No: DF.22
Your Ref. No:

14th November, 2012

ETHICAL CLEARANCE

FEDERALWIDE ASSURANCE FWA 00001824 **IRB 00001276**

NMIMR-IRB CPN 023/12-13 **IORG 0000908**

On 14th November, 2012, the Noguchi Memorial Institute for Medical Research (NMIMR) Institutional Review Board (IRB) at a full board meeting reviewed and approved your protocol titled:

TITLE OF PROTOCOL : **Experiences of Caregivers of Individuals with Schizophrenia in the Accra Metropolis**

PRINCIPAL INVESTIGATOR : **Florence Animwaa (MPhil Student)**

Please note that a final review report must be submitted to the Board at the completion of the study. Your research records may be audited at any time during or after the implementation.

Any modification of this research project must be submitted to the IRB for review and approval prior to implementation.

Please report all serious adverse events related to this study to NMIMR-IRB within seven days verbally and fourteen days in writing.

This certificate is valid till 13th November, 2013. You are to submit annual reports for continuing review.

Signature of Chairman: .....
Rev. Dr. Samuel Ayete-Nyampong
(NMIMR – IRB, Chairman)

cc: Professor Kwadwo Koram
Director, Noguchi Memorial Institute
for Medical Research, University of Ghana, Legon

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APPENDIX C: SITE APPROVAL LETTER

SCHOOL OF NURSING
COLLEGE OF HEALTH SCIENCES
UNIVERSITY OF GHANA
LEGON

Telephone: 021-513255 (Dean)
Ext. 6206
021-513250 } Secretary
028 9531213
Fax: 513255
E-mail: nursing@ug.edu.gh

P. O. Box LG 43
LEGON, GHANA

Our Ref: SON/F.11
Your Ref:

November 21, 2012

The Medical Director
Pantang Psychiatric Hospital
P.O. Box LG 81
Legon - Accra

Dear Sir/Madam,

APPLICATION FOR SITE APPROVALTO CONDUCT A RESEARCH STUDY AT THE PANTANG PSYCHIATRIC HOSPITAL

Title of Project: **Experiences of Caregivers of Individuals with Schizophrenia in the Accra Metropolis**

Principal Investigator: Florence Animwaa

This letter is to request your permission and assistance for the researcher for her study on the Experiences of Caregivers of Individuals with Schizophrenia. She is an M.Phil research student of the School of Nursing, College of Health Sciences, University of Ghana, Legon

The participants will be informal caregivers of individuals with schizophrenia who attend reviews at your facility. Data collection will involve interviews with the informal caregivers at the location of the participants' choice.

Please find attached a copy of the ethical clearance letter from Noguchi Memorial Institute for Medical Research (NMIMR) and the consent form for prospective participants.

I kindly request your assistance to the researcher.

Yours faithfully,

Prudence P. Mwini-Nyaledzigbor (Dr.)
SUPERVISOR

Cc: The Chairman Ethics Committee
The DDNS i/c
The Psycho OPD
Psychiatric Social Welfare Unit
Biostatistics Unit

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APPENDIX D: CONSENT FORM

Title of study: Experiences of Caregivers of Individuals with Schizophrenia in the Accra metropolis

Researcher: Florence Animwaa, M'Phil Nursing Student, University of Ghana.

Address: School Of Nursing, University Of Ghana, Legon (M'Phil Nursing Student).

Telephone numbers: 0246963284/ 0277249275

Supervisors: Dr. Prudence Mwinituo Nyaledzigbor and Dr. Daniel Kojo Arhinful

General information about the study

Dear Respondent,

You are being invited to part take in a research study. Before you decide, it is important for you to understand why the research is done and what it will entail. Please take time to read the following information about the research carefully.

Purpose of Study

This study seeks to explore Experiences of Caregivers of Individuals with Schizophrenia in the

Accra metropolis

The purpose of this study is to examine the experiences and perceptions of caregivers of individuals with schizophrenia with an overall aim to develop and test new strategies to support Ghanaian family caregivers.

In order to carry out this study, I want to interview family care givers of individuals with schizophrenia. The interviews will be tape- recorded lasting for 45mins. – 1hour.

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I will be the only one present to conduct the interviews. Each participant‘s privacy will be strictly ensured. No name will appear on the transcript and no identifying information will be included. The audiotapes will be kept in a locked cabinet for at least five years after the study is done.

Possible Risks and Discomforts

There are no known risks to participating in the study. You do not have to be in the study if you don‘t want to. Your participation is voluntary and withdrawal is without any consequences. This study is being done for a Master‘s thesis and there are plans to publish the findings in academic journals and presentations at research conferences. Data will always be presented as group data. No individual participants will be identified.

Possible Benefits

As a participant, you may feel relieved after sharing your care giving experiences with the researcher who is herself a psychiatric nurse.

Findings of this study will provide nursing knowledge to improve support for family caregivers. The study will provide knowledge of caregivers‘ experiences to policy makers

Alternatives to Participation

Instead of being in this research study you can also choose not to participate.

Confidentiality

Confidentiality is essential; the researcher will safeguard participant‘s identities and responses from public disclosure. The researcher will ensure confidentiality of participants at all times. Pseudonyms will be used throughout the study. Participants will be assigned an identification number which will be used throughout the study and no identifying information will be entered onto computer files. The only persons who will have access to the research records are my supervisors and external examiners without your permission.

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Compensation

There will be no compensation or fee paid to the participants participating in the study.

Voluntary Participation and Right to Leave the Research

You are free to participate in this study or to withdraw your consent and discontinue participating in the study at any time without any punishment or intimidation towards you or your patients.

VOLUNTEER AGREEMENT

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

....

Date Name and Signature or Mark of Volunteer

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

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

....

Date Name and signature of witness

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

....

Date Name and Signature of Person Who Obtained Consent

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APPENDIX E: INTERVIEW GUIDE FOR THE RESEARCH.
Data Collection Instruments (i.e. Interview Guide, Questionnaire, etc)
Title of study: Experiences of Caregivers of Individuals with Schizophrenia in the Accra Metropolis

Researcher: Florence Animwaa, M'Phil Nursing Student, University of Ghana. **Address:** School Of Nursing, University Of Ghana, Legon (M'Phil Nursing Student). **Telephone numbers:** 0246963284/ 0277249275

Supervisors: Dr. Prudence Mwinituo Nyaledzigbor and Dr. Daniel Kojo Arhinful

This list of questions will guide the researcher. It does not have to be adhered to systematically or completely. The participant's response will also guide the questions.

The interview guide will contain a list of open-ended questions which have been derived from the objectives of the study. These open-ended questions must be balanced, unbiased, and clear (Whitehead & Annells 2007)

DEMOGRAPHIC DATA

1. Participant's Label/ Pseudonym
2. Age of the caregiver.....
3. Gender of caregiver…….....
4. Educational level of caregiver…….....
5. Occupation of caregiver…….....
6. Marital status of caregiver……....
7. Religious affiliation of caregiver …….....
8. Gender of patient …….....
9. Educational level patient …….....
10. Marital status of patient …….....
11. Relationship of caregiver to patient …….....
12. Length of care …….....
13. Languages spoken …….....

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Guiding Questions

1. Can you please tell me about yourself?

2. Please tell me what a typical day is like for you as a caregiver

Probes:

 Tell me how you maintain the patient‘s activities of daily living like oral care, physical

cleanliness, nutrition and elimination.

 Is there anything else you would want to add? E.g. Problems, stigma, negative reaction from people etc

3. Please tell me how the patient participate / influence in the care. Probes:

 Resist to grooming?

 React violently?

 Threatens to harm himself, you or others?

4. Please tell me how it is like in providing care to a schizophrenic patient.

Probes:

 Is it irritable?

 What about financial issues?

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APPENDIX F: CHARACTERISTICS OF PARTICIPANTS

Participants' Label/	Age	Gender	Educational level	Occupation	Marital status	Relationship to patient	Length of care	Language spoken
P1- Naa	68	Female	'O' level	Retired	Divorcee	Daughter	30yrs	English
P2-Fiadzo	74	Male	Polytechnic	Retired	Married	Son	19yrs	English
P3-Araba	54	Female	Elementary	Daycare	Married	Son	11yrs	Twi
P4- Nkansa	54	Male	Elementary	Businessman	Married	Wife	3month	Twi
P5- Sena	26	Female	Polytechnic	Sales	Single	Cousin	6yrs	English
P6-Kukua	38	Female	Primary six	Seamstress	Single	Aunt	15yrs	Twi
P7- Okaine	46	Male	University	Electrical	Married	Brother	25yrs	English
P8- Dzifa	53	Female	Elementary	Ward	Separate	Son	8yrs	English
P9- Serwaa	46	Female	Masters	Tax	Married	Aunt	20yrs	Twi
P10- Nii	24	Male	University	Student	Single	Grandmother	5yrs	English
P11-Adoma	70	Female	None formal	Unemployed	Widow	Son	18yrs	Twi
P12- Ocancy	23	Male	High school	Student	Single	Mother	2yrs	English

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