

**THE INTERFACE BETWEEN THE HEALTH PROFESSIONALS AND LAY  
CAREGIVERS AT THE KOFORIDUA CENTRAL HOSPITAL IN THE EASTERN  
REGION OF GHANA**

**BY**

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**THIS THESIS IS SUBMITTED TO THE UNIVERSITY OF GHANA, LEGON IN  
PARTIAL FULFILMENT OF THE REQUIREMENT FOR THE AWARD OF PHD  
SOCIOLOGY DEGREE**

**JULY, 2017**

## DECLARATION

I declare that this thesis is my own original work carried out in the Department of Sociology, University of Ghana, Legon and under the supervision of Prof. Kodjo Senah, Dr. Kofi Ohene-Konadu and Dr. Peace M. Tetteh, all of the Sociology Department. Where references have been made to other people's views and works, full acknowledgement has been made. I further declare that as far as I am aware, this work has not been submitted anywhere for a certificate or a degree. Finally, I declare that although I received various forms of assistance towards the write-up of this thesis, I hold myself solely responsible for any misinterpretation and or misrepresentation of facts that may occur in this thesis.

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## **DEDICATION**

This work is dedicated to my sweet, hardworking and soul-inspiring mother, Mrs. Edith Norvi Adjo Agbenyefia, who never went to school but sacrificed to single handedly take care of all ten of us and has positioned us to face life's challenges. Davi, your words of advice are what have brought me this far. You are indeed, the virtuous woman described in Proverbs 31:10-31.

## ACKNOWLEDGEMENTS

*How can I repay the Lord for all his goodness to me? I will lift up the cup of salvation and call on the name of the Lord. (Ps 116:12-13 NIV)*

Indeed, there is no way I can repay the Lord for His goodness to me. I am, therefore, grateful to Him for how far He has brought me in the pursuit of my academic ambitions. I owe all thanks to Him for his protection, travelling mercies and wisdom granted me through these hectic four years.

I am grateful to my supervisors, Dr. Kofi Ohene-Konadu, Dr. Peace M. Tetteh and most especially Prof. Kodjo Senah who went beyond being a supervisor to be my counsellor, guide and sympathiser during several trying moments I went through. I appreciate all your contributions that helped in shaping this work.

I am similarly grateful to the Medical Director, the Administrator, the Head of Research Team, Pharmacist, Seth Twum and the ward matrons of the two adult medical wards all of the Eastern Regional Hospital, Koforidua for their assistance during my 17-month work in the hospital. Special mention must also be made of these three nurses for their unflinching support and warm receptions: Madam Dorothy Agyapong Takyi, the then Deputy Director of Nursing Services (DDNS) in charge of the medical wards who gave me a warm reception and offered me the Doctors' Rest Room to use for my private studies, Madam Mary Ofosua Dokuaa and Madam Dina Donkor who always met me with smiles and affection anytime I arrived in their wards. I cannot describe how such warm receptions made me feel at home. May God bless them all. I also appreciate the contributions of all nurses, doctors, caregivers and patients who participated

in this study. To Mr. William Kwesi Hammond and Mr. Samuel Obeng, I say God bless you for assisting me to transcribe the data.

I am indebted to Dr. Akosua Darkwah, whose words influenced me greatly to change the study site when I was facing challenges with Korle-Bu Teaching Hospital's bureaucratic procedures. My indebtedness is also extended to all lecturers of the Sociology Department, University of Ghana, especially Dr. Dan-Bright Dzogbo, Dr. James Dzisah and Dr. Samson Appiah, for their various contributions towards the completion of this work. Dr. Lydia Aziato of the School of Nursing, University of Ghana also deserves acknowledgement for her words of inspiration and direction.

I am also most grateful to my family members especially, my sweet mother, for assisting in caring for my children in my absence and to my husband for his financial support and words of encouragement. To my lovely children, Seyram, Delase and Sena, God bless you for being patient with me. Thanks to my brothers, Evangelist George Kafui Kwaku Agbenyefia, Overseer Emmanuel Emerald Kwame Agbenyefia and all other siblings for their prayers and moral support.

I also want to extend my sincere gratitude to all members of the Church of Pentecost, OPASS Assembly, especially, Elder S.O Bekoe and his wife for their prayers and to the executive members of the Women's Ministry, especially my assistant, Deaconess Comfort Akwei, for holding the mantle in my absence. To my friend, counsellor and co-worker, Mrs. Christiana Obenewaah Tenkorang, I cannot find words most appropriate to describe how much I appreciate all your contributions towards my development. You are a friend indeed!

Finally, my colleagues in the Sociology Department, the pioneers of the University of Ghana 4-year PhD programme, especially, Mary Sefa-Boampong, Salifu Abukari and Ramatu Dadzie, I say thank you for your words of encouragement.

## **ABSTRACT**

In Ghana as in many developing countries, the quest to provide quality professional health care for patients in the hospital is confronted with many challenges. However, the challenges are evidently articulated in the ward where all the medical challenges coalesce. In Ghana, beside other medical challenges, shortage of professional staff is a great barrier to providing quality patient care. The desire to fill this professional lacuna has, by default, resulted in the use of lay caregivers to provide medical care needs for in-patients. Globally, both developed and developing countries use lay caregivers but in different respects. Lay involvement in health care delivery is believed to add emotional value to the patient's therapeutic process. As a result, much has been written on the contributions of lay caregivers in the home, hospice, home for the aged and hospitals. In spite of the usefulness of lay caregiving in the hospital environment, not much is documented on the extent to which lay caregivers go and how they negotiate their roles with the health professionals in the hospital context.

Ghana is one sub-Sahara African country that depends heavily on lay caregivers in the hospital due to inadequate health professionals. In spite of this, there are no clear policies on lay caregivers and neither are their services officially recognised. This hospital ethnographic study, therefore, explored the factors that influence lay caregiving in the hospital environment, the extent to which this is carried out in the therapeutic process and how lay caregivers negotiate their roles with health professionals within the hospital context in a Ghanaian public regional hospital.

The study involved interviews with patients in a medical ward, nurses, doctors and lay caregivers. In all, 32 lay caregivers and 12 in-patients were interviewed. Eight (8) key informants made up of six nurses and two medical officers (doctors) were also interviewed.

The study revealed that lay caregivers' involvement in care is influenced by institutional, socio-cultural and other situational factors. Institutionally, shortage of staff and negative attitude of some health professionals were the main influencing factors. Socio-cultural factors such as the demands of primordial ties - reciprocity and kinship moral obligation were outstanding. Other significant situational factors include the severity of a patient's condition, (eg non-ambulatory condition and incontinence) and mistrust of professional health care providers. Negotiation between health professionals and lay caregivers is influenced by a compromise based on win-win approach. The study concluded that although health care providers and lay caregivers appreciate the rationality of the irrational situation, both parties were satisfied in the end: in the face of severe staff shortage, health professionals are assisted to provide care to the sick while lay caregivers derive emotional satisfaction from carrying out their moral responsibility to their sick relations who may not receive love and tender care from health professionals.

It is recommended that as a short term measure, the Ministry of Health in conjunction with the Ghana Health Service should formulate policies that create room for lay caregivers' involvement in provision of care for in-patients in the hospital. However, to get a permanent solution to provision of quality professional care for patients, there is the need for government to recruit more health personnel to reduce the workload on the few working in the wards. Logistics such as modern BP apparatus, pulse oximeter, sophisticated laboratory and x-ray equipment and adequate drugs should be supplied to the hospitals to make professional work very effective and to reduce reliance on lay caregivers.



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## **ACRONYMS**

DDNS:	Deputy Director of Nursing Services
FMC:	Free Maternal Care
HP:	Health Professional
HM:	Hospital Minister
HS:	Hospital Security men
IPD:	In-Patient Department
KCH:	Koforidua Central Hospital
LC:	Lay Caregiver
MO:	Medical Officer
NHIA:	National Health Insurance Authority
NHIF:	National Health Insurance Fund
NHIL:	National Health Insurance Levy
NHIS:	National Health Insurance Scheme
NHLMC:	National Health Learning Manual Commission
OPD:	Out Patient Department
PHC:	Primary Health Care
SWD:	Social Welfare Department

VAT: Value Added Tax

VH: Visitors' Hostel

WM: Ward Matron



## CHAPTER ONE

### THE CONTEXT OF HEALTH CARE

#### 1.0 Introduction

Ghana's health care system is at the crossroads. The dilemma is not only about how quality health care could be made accessible in terms of infrastructure or affordable with respect to financing, but also, the lack of personnel needed to provide such quality care. Governments over the years have instituted several measures to provide quality professional health care to the citizenry but this dream appears to be a mirage.

The researcher met a group of relatives of patients at the summer hut of the Eastern Regional Hospital (ERH) one afternoon when she went to visit a friend. Based on her admission experiences at Korle-Bu Teaching Hospital some years ago and how her husband and mother went through difficulties in commuting from Madina, (a suburb of Accra) to Korle-Bu twice daily to ensure that her care needs were met, the interest to investigate the contributions of lay caregivers was developed. Later when permission was granted her to do the study, a discussant of a focused group discussion made a soul-touching statement which set the tone for this study. The discussant lamented:

*“It is the responsibility of the hospital staff to provide proper care for patients when they are brought to the hospital but this is not the case. That is why those of us who brought the patients have to be around and care for them. My relative has been on admission for the past one week and if I should tell you the difficulties I am going through, you will not believe it. I have contracted some diseases due to my stay here but if I want to leave the patient here and stay home, it will be difficult for me to attend to him because I am not from Koforidua. I am from Abomoso area and the place is far. Going home and coming back will cost me twenty-two (GH¢22) Ghana cedis daily. If I should be going to and fro*

*every day, where is the money? So, I have to stay around. Here we are, sitting down under this hut and do not even know where to sleep!”(Kojo)*

The statement above was a response given by a discussant and was supported by other members of the group when they were asked why they were sitting under the summer hut at the hospital. One will therefore ask why these people would leave the comfort of their homes to stay in the hospital to care for the sick at the expense of their own health. The answer is simply to provide care to augment the care provided by the health professionals.

This statement also depicts the current health care situation in most public hospitals in Ghana. The involvement of lay caregivers in the hospital environment is not a new phenomenon; it is a global phenomenon found in both developing and developed countries. In developed countries such as the United States of America (Tzeng & Yin, 2011) and the United Kingdom, due to the increasing numbers of people with chronic and degenerative diseases, lay caregiving has increased. In countries such as South Africa (Danielson, Brenda, & Patricia, 1993), UK (OECD, 2011) and USA (Family Caregiver Alliance, 2016), policies exist and education is often carried out on the need and benefits of informal or lay caregiving. Developing countries including Ghana where there are no clear-cut decisions or policies on lay caregiving have lived with the phenomenon and pay little or no attention to it even though lay caregivers are a stop-gap measure for the shortage of professional staff. Lay caregiving in a professional environment has become a necessity to family members for the reason that ill-health is a fact of life; in its severe form, it is disruptive and exacts a heavy toll not only on the sick, but also on their social network. Every society, therefore, develops pragmatic ways of dealing with ill health - from its definition to perceived causation and prevention to therapy management (Senah, 1981). Janzen (1978/1982) indicates that, in Lower Zaire, many people believe that the medical doctor cannot treat certain

diseases hence such diseases must be taken to a “diviner-seer” or the traditional healer. To him, the traditional healer and untrained caretakers use efficient measures in providing immediate health care needs for the sick. He indicates for example that family members are seen around the sick sometimes feeding the patient, conversing with him/her and at other times just sitting idly or washing his or her clothes. He reports that the family members are always around the sick even at the hospital to the surprise of the Western-trained hospital staff, who feel that the patient should be left alone to rest and recover. Kinsmen, therefore, play a very significant role in determining the kind of treatment the sick must go through.

As Jansen (1978/1982: 4) further states, “the management of illness and therapy by a close kin is a central aspect of the medical scene in Central Africa. In order to provide the needed health needs of their members, a therapy managing group which consists of kinsmen and/or their advocates comes into being whenever an individual or sets of individuals become ill. The therapy managing group exercises brokerage function between the sufferer and the specialist whether Western treatment or traditional practitioner”.

Writing on the Shona of Zimbabwe, Machinga (2011) indicates that in Shona culture, good health is measured from the cultural understanding of the role of the family, community and the spiritual world in human welfare. Diseases are considered to have multiple causes and as a result, treatment goes beyond physical symptoms. The health and healing system of the Shona is therefore all-encompassing as it considers both personal and communal obligations as important in all aspects of life. The communal obligation to the healing process involves the participation of family members of the sick. Other community members are also involved in the healing process since ill-health of a member of the community affects the proper functioning of the community. The healing process, therefore, goes beyond the individual sufferer to include his or

her social relations as a good interpersonal relationship is considered very important for good health. Rituals of all forms involving the total social network of the sick are performed before he/she leaves the traditional healer's premises. This communal context of healing is also reported among the Zulu by Washington (2010:30) as he states: "Zulu healing occurs within the communal context and it is the responsibility of the community to facilitate the healing of the family, couples or individuals because the illness as well as the wellness impacts the entire community".

As found in many other sub-Sahara African countries, in Ghana, lay involvement in health care delivery is not a new phenomenon. In the pre-colonial era, hospitals did not exist and health care services were primarily provided by traditional medicine practitioners using a variety of remedies and treatments (Addae, 1997). These healers tackled health care from a multi-dimensional perspective by attending to both health and spiritual needs of their clients. This multi-faceted dimension of healing is based on the common assumption that, every physical phenomenon has its spiritual aspect and health or illness issues are no exception. Treatment of ill-health was therefore holistic. According to Akrong (2009:96), "healing in African traditional society is based on the principle that health is a holistic and multi-faceted process which has spiritual, social, psychological and environmental or cosmic dimensions. Illness from this perspective is viewed as the result of disharmony or disequilibrium in the life of the individual that may involve a number of factors in the personal life of the individual or the community or the environment"

Traditionally, those seriously ill were the charge of family members, friends and neighbours who played very important roles in their care either at home or the shrine, in the home of the traditional healer and spiritual healing centres (Akrong, 2009; Sackey, 2009; Senah, 1981;

Twumasi, 1975). When a patient is sent to the shrine for treatment, relatives stay with him at the shrine until he is well and discharged. Twumasi (1975) further states that, the patients' relatives must appoint what he calls an "okyigyinafo" (someone who will support the sick) to remain with the patient during the course of treatment at the shrine and refusing to appoint an "okyigyinafo" will be a "standing reproach" to the whole extended family unit. This implies that when a member of a family is sick, somebody must stay with the sick no matter where the sick was receiving treatment whether at the shrine, religious healing centres and home of traditional healers or herbalist and even at the hospital. Relatives or non-relatives who provide these care services in the hospital environment are the concern of this study and they are referred to as lay caregivers (LCs).

In the context of cultural philosophy, Sackey (2009) bases care for the sick on two proverbs as found in Akan tradition and in other ethnic groups in Ghana. The first of the proverb is rendered thus: "Se obi hwewo ma wose fifir a, wo so hweno mane se tutu" (if someone takes care of you to grow your teeth, you must also take care of the person till he/she loses his/her teeth). The second is that "nsa benkum guare nyinfa na nyinfa so guare benkum" (the left hand washes the right hand and the right hand washes the left)". Based on these proverbs, it can be concluded that caregiving is both a moral obligation and reciprocity of the caregiver to the care recipient (the sick). In addition to the above, caregiving also meets another cultural practice in that among the Ewe of Ghana, it is customary for a relative to give the dying water to drink before the individual passes on. Also, from the cultural perspective, it is improper for someone outside the family to see the nakedness of a kin member being bathed; bathing is considered an essential component of health care for the sick (Sackey, 2009).

However, the arrival of the Europeans in the Gold Coast brought a new system of health care delivery into the country where sick people no longer received medical attention at home, in the shrine or in the homes of traditional healers but in health institutions. The two systems were utilised concurrently by the indigenes and as a result, the first civil colonial hospital was built in Accra in 1878 (Addae, 1997). Addae (1997:11) further adds that “the most important difference between the African and the European approaches to medical care was an organizational one where the European and other cultures founded hospitals, clinics and dispensaries or their equivalents where the sick could be attended to in an organised way and that no such equivalent appears to form a part of the Ghanaian African healing methods.” Badasu (2009:150) however states that “the two systems differ with respect to explanations of cause of disease as well as the approach to prevention and cure”.

Even though the local people initially resisted their incorporation into the new medical system, opposing being cared for by the Europeans rather than relatives and also being quarantined, hospital admission and care have come to stay and as more efficient technologies were developed, hospitals were built all over the country and became the most preferred place for patients seeking medical attention. This is partly due to the fact that during the colonial era, workers in government services were required to seek medical aid from the services of scientific medical institutions and also provide medical certificate as proof of disability (Twumasi, 1975).

This new system of providing health care was a sharp departure from the traditional system where family members and neighbours played very important role in health care delivery. Also, the new system has gradually removed the care of the seriously sick from the domain of the family and other lay caregivers to the hospital to be cared for by professionals unrelated to the

sick. With increased acceptance of allopathic care in times of ill health, one expects less and less participation of lay caregivers in the care of the institutionalised sick.

Even though the traditional and allopathic modes of care delivery coexist on parallel basis, for some time now, these modes are becoming interdependent. The activities of lay caregivers in the traditional system are found in the hospitals these days while some traditional healers prescribe allopathic medicine for their clients. It must be noted that even though lay caregivers do not originally form part of the philosophy and practice of the formal health care system, the family and other lay caregivers play significant roles in the treatment of patients at the hospital. Their services can provide sufficient and effective emotional and psychological support for patients receiving medical attention in hospitals (Aziato & Adejumo, 2014; Laitinen, 1993; Lavdaniti et al., 2011). It is, therefore, important that the health professional (HPs) maintain a good relationship with these lay caregivers and provide them with the appropriate information needed for effective handling of the sick.

Lay caregiving is therefore becoming an important part of health care delivery to provide proper care for the sick. However, the extent to which lay caregivers could go in an institutionalised environment needs to be defined to avoid complications which may arise as a result of inadequate knowledge in handling certain health conditions by the lay caregivers. Conditions that necessitate lay caregiver's involvement in institutionalised care, the benefits and peculiar problems that lay caregiving could pose are the matters of concern this study aims at discovering.

Ugochukwo, Uys, Karani, Okoronkwo and Diop (2013), state that even though it is recognised that the family plays a role in the care of ill family members around the world, in many low-resourced sub-Saharan African countries, care in hospitals, including food and medication, are

supplied by the family and a family member stays with the patient most of the time. These family members also render certain key services which are supposed to be the preserve of the health professionals. To them, this may be by default rather than design. This study is therefore about the dynamics of the nexus between lay and professional health care giving in an institutional health care environment.

### **1.1 Statement of the Problem**

The health care sector had its fair share of the economic crisis that hit Ghana in the 1970s. This has negatively affected the quality of care provided for patients. Shortage of logistics, high cost of health care and inadequate personnel are some of the consequences of the economic crisis. Even though efforts have been made to improve the situation, much has not been achieved. A visit to many public hospitals with admission wards indicates the extent to which lay caregivers are actively involved in health care giving. Within some wards, lay caregivers are allowed to share limited spaces with the sick; and others are made to run errands normally undertaken by the nursing and paramedical staff. Consideration for the risk of opportunistic infection is relegated to the background. A casual visit to the Koforidua Central Hospital during the day and at night reveals a heavy presence of lay caregivers providing one form of care or the other to their hospitalised relations. However, hospitals, like most formal organisations are specialised institutions. Specialization or professionalism establishes an asymmetrical relationship between the professional and the non-professional. According to Freidson (1972), the professional is knowledgeable in his field while the non-professional is not. Thus, there is a super- and subordinate relationship between the lay caregiver and the medical staff. All formal organisations such as the hospitals have a structure and within this structure, every functionary is placed in a stratum with clearly defined functions. The hospital which depends greatly on professional



knowledge is highly stratified with staff performing their clearly defined functions. Sidel and Sidel (1981) in Conrad and Kern (1981), state that the first contact with the professional medical system is often with professionals. These include pharmacists, nurses, dispensers, physicians etc. and these are supposed to provide all the basic health care needs of patients who report at the hospital.

The Koforidua Central Hospital like any health institution in Ghana has its organisational structure that articulates organisational interdependence and clearly demarcated roles. As a referral hospital with different departments and centers, it is assumed that the care needs of in-patients will be provided by the hospital staff with minimum involvement of the kingroup or anybody outside the health profession who are referred to as lay caregivers in this study. At the minimum, these lay caregivers are to visit and provide financial and some emotional needs of their loved ones. In spite of the complexity and specialization of health care, it is evident that today, the family still plays a significant role in the event of serious ill health even in the hospital. Meanwhile, within the structure of KCH (as shown in figure 1.1), no place is allocated for lay caregivers in the care delivery system. The involvement of lay caregivers is therefore considered unwanted. Even though these lay caregivers do not form part of the philosophy and practice of health care delivery, data revealed that they play very important roles in complementing the services provided by the professionals. However, they are limited in or prevented from performing certain functions due to bureaucratic processes and logic of hospital authority and responsibility.



connected with physical health. Hence for holistic care, spiritual care needs must be provided. There is also a large volume of literature on lay care provision for patients with cancer, dementia, HIV (Wacharasin & Homchampa, 2008) and terminal cases (Mcmillan, 2005) with little attention paid to temporal or short term ill health conditions such as severe malaria and other general health conditions. Literature also abounds on the care for hospitalised children (Altimier, 2015; Wegner & Pedro, 2009) and adults in surgical wards while much is not documented on the care for the hospitalised adult in the medical wards.

As indicated earlier, originally, lay caregivers do not form part of the philosophy and formal practice of health care in the hospital. However, even though much has been written worldwide on the contributions of lay caregivers within the hospital setting, not much is written on how they are able to negotiate their roles with the professional staff within the professional setting. Even though some literature exists on how health professionals negotiate their roles with family caregivers in Western culture (Kirk, 2001; McCann et al., 2008; Ward-Griffin, 1998), little is known about this in a non-Western culture such as Ghana. Much is also not documented on the extent to which lay caregivers could go in care delivery at the hospital. As it has become clear that lay persons are getting actively involved in professional care, the critical questions then are: what roles are lay caregivers allowed to play in the therapeutic process and how do the lay caregivers and professional caregivers negotiate their roles in a context where professionalism is the norm?

### **1.2a. General Objectives**

Broadly, this study seeks to examine the nature and dynamics of lay care giving at the Koforidua Central Hospital. The ultimate aims are to inform policies on general care for the hospitalised and to contribute to the literature on institutional care in a non-Western context such as Ghana.

### **1.2b. Specific objectives**

In furtherance of the main objective, the study focuses on the following specific objectives:

- a. To determine the socio-cultural factors that influence lay caregivers to provide care;
- b. To investigate institutional factors that facilitate as well as hinder lay care giving
- c. To examine patients' and medical staff's views on lay care giving in the hospital context.
- d. To find out how lay caregivers and health professionals negotiate their roles within the hospital settings.

### **1.3. Significance of the study**

The study offers the opportunity to interrogate the processes of enculturation of alien institutions and the consequences. At this time when the state is gradually pushing for domiciliary care for many health conditions, this study may open the window for a serious discourse on the issue. The findings of the study will also enhance knowledge in sociology of health and organizational behaviour.

Since organisations operate in a social environment and social change is inevitable, the findings will inform policy makers on the changes taking place in formal organisations and how to meet such social changes. Findings will further influence organizations and policy makers interested

in health issues. The study will also bring to the fore the important roles played by lay caregivers and therefore influence policy as to their involvement in care for the hospitalised.

#### **1.4. Definition of Key Concepts**

For a better understanding of this study, the following key concepts have been explained: lay caregiver, care and health professionals.

##### **Lay Caregiver**

Lay caregivers are called differently by different authors. Some call them informal caregivers (Bragstad, Kirkevold, Hofoss, & Foss, 2014; Hayman et al., 2001), non-staff visitors (Tzeng & Yin, 2011), family caregivers (Aziato & Adejumo, 2014; Duncan & Morgan, 1994), family-centered care (Altimier, 2015), lay practitioners and others, lay caregivers (Faria & Schall, 1997). Family caregiver according to Blum and Sherman (2010) refers to any relative, partner, friend, or neighbour who has a significant personal relationship with and provides a broad range of assistance for a person with a chronic or disabling condition. In this study, the term is used liberally to mean people who are not health care professionals, but who are responsible for providing care for in-patients at the hospital. This includes kinship and non-relatives such as neighbours, co-workers and friends. For the purpose of this study, a relative who is a health professional but is not on an official duty but comes to the hospital to provide care for a relative due to the social tie that exists between them will be considered a lay caregiver.

##### **Care**

Even though Leininger (1991b) defines care as those assistive, supportive and enabling experiences or ideas towards others with evident or anticipated needs to ameliorate or improve a

human condition or life way, care in this study refers to the process of looking after and protecting the sick.

### **Health Professionals**

Health professionals refer to the trained personnel in the hospital environment who perform the functions of medical or health care delivery in the hospital and for this study, these include, nurses, medical doctors and paramedic staff (eg. laboratory technicians and pharmacists)

### **1.5. Organization of the study**

The study is organised into nine chapters. Chapter One provides a brief introduction to the study by specifying its background giving global and local views on care and the motivation for the study. The chapter also focuses on both the general and specific objectives and highlights the significance of the study.

Chapter Two is dedicated to the review of existing literature on lay caregiving and negotiation and discusses the theoretical framework within which the work is situated.

The methodological approaches used in data collections and the field experiences are described in Chapter Three whereas Chapter Four provides a brief background to Ghana's health care system and the effort made by various governments to make health care accessible and affordable to the citizenry.

In the presentation of data, Chapter Five discusses lay caregivers in the hospital environment paying attention to their experiences, modes of adaptation and challenges that confront them while Chapter Six discusses factors that influence care giving. The patients and their experiences are also described in Chapter Seven. Here, their relationship with the health professionals and

other patients is given special attention. Their challenges and coping strategies are also examined.

Chapter Eight focuses the “love-hate relationship” between the health professional and the lay caregivers and the complementary roles played by the caregivers. The chapter also discusses the value of lay caregivers in the therapeutic process and how they negotiate their roles with the health professionals.

Finally, Chapter Nine provides a reflection on the study by summarising the main findings and making recommendation for policy implementation and future research.

## **CHAPTER TWO**

### **LITERATURE REVIEW AND THEORETICAL FRAMEWORK**

#### **2.0. Introduction**

The issue of lay caregiving in health institutions has gained respectable attention in medical sociological discourse. This may be due to the misgivings people hold about the quality of health care and the future of professional health care delivery system. Different scholars have identified different reasons for and or roles of lay involvement in health care delivery across the world. Whereas some lay caregivers and nurses call for lay involvement in health care delivery (Herath, 2014), others see lay involvement in professional health care delivery as by default rather than design (Ugochukwo et al., 2013). Some researchers have also written on countries where lay caregivers are used as a means of providing holistic care for hospitalised patients. Whereas Lavdaniti et al. (2011) and Sapountzi-Krepia et al. (2008) wrote extensively on Greece, Tzeng & Yin (2011) for example wrote on the phenomenon in the USA. Some studies have also been carried out in some African countries such as South Africa (Daniels, Clarke, & Ringsberg, 2012; Pletzen, 2013) and Ghana (Ae-Ngibise, Doku, Asante, & Owusu-Agyei, 2015; Aziato & Adejumo, 2014).

#### **2.1. The Concept of Lay Caregiving**

Ill-health is one of the conditions under which the sick will need the help and care of others. This care may be provided by both professionals and lay people. Ward-Griffin and McKeever (2000) indicate that the need for involvement of family caregivers has become common in health care delivery in Canada for example, due to what is called financial “health care crisis” coupled with acute shortage of beds in hospitals for chronically ill people. They also identified an increase in



the growing proportion of older people with disabilities and chronic illnesses as a factor influencing lay caregiving. Stavrou, Zyga, Voulgaris, and Sgantzios (2014) report that research on in-hospital informal care in Greek hospitals started from the early 1990s as a result of nursing staff shortage and cultural influences on health care provision patterns while Solbjør, Rise, Westerlund and Steinsbekk (2013) indicate that during the 1980s and 1990s, the Norwegian government initiated reforms to modernise public services resulting in a rise in user involvement in health care in the 1990s.

The usefulness of lay caregivers both at home and the hospital cannot be over emphasised. Ghana's Patient Charter (option (d) under the Code of Ethics) states that "All service personnel shall co-operate with the patients and their families at all times". This is to say that in Ghana, the involvement of family members or the network of social relations in the health-care delivery system cannot be discounted. There is also a global call for the involvement of lay people in health care delivery. According to Doherty and Mendenhall (2006) the Citizen Health Care model calls for patients and families to become active participators in health care. To this model, "patients and families have wisdom that is not "medical" or "technical", but still, is as equally important as their health-care providers" (Doherty and Mendenhall, 2006: 253). The Citizen Health Care is a way to engage patients, families, and communities as co-producers of health and health care. According to Tzeng & Yin (2011) the movement to embrace family and non-family visitor-involvement in bedside patient care started in 2007 and the USA Joint Commission has stressed the need to define and communicate ways for patients and their families to report concerns about safety and encourage them to do so. They explained that the rationale behind this movement is a belief that patients and their visitors have important roles within health care teams by identifying potential medical errors and preventing hospital-acquired injuries. It is, therefore,

a common belief that having at least one familiar face accompanying the sick child at the hospital, for example, may promote the healing process and decrease study stress levels caused by staying in unfamiliar surroundings and undergoing medical treatment and procedures. The former President of the United States of America, Barrack Obama acknowledging the useful contribution of lay caregivers declared November, in 2009 as National Family Caregivers Month.

In the United Kingdom for example, the National Strategy for Carers emphasises the importance of providing information for carers, supporting carers in their caring activities, promoting their health and social wellbeing and maintaining their other roles, including paid employment (Department of Health, 1999).

Discussing regulation and reality, Badasu (2009) states that in Ghana, until about the late 1970s, relatives of patients in public hospitals were not expected to stay with them in the wards except in some emergency cases and that nurses were responsible for both bedding and feeding of patients. Relatives and visitors were allowed to see patients during visiting hours. However, due to the shortage of nursing staff in the 1980s, family involvement in in-patient care has become the norm rather than a choice

## **2.2. Lay Caregivers and the Sick**

Reasons for helping the sick could be grouped under factors such as socio-cultural, institutional, altruism, egoistic motives and economic. Some theorists have defined or explained the reasons why people help others.

Literature reveals that some lay caregivers offer help because they see it as moral obligation, affection towards the sick, maintaining family values and preserving family dignity (Wacharasin

& Homchampa, 2008). Caregiving also occurs as a result of societal expectations of family and the obligations of family members to one another or as a form of reciprocity (Goodhead & McDonald, 2007). del-Pino-Casado, Frías-Osuna and Palomino-Moral (2011) however, report that obligation and reciprocity is common among spouses than among other relatives and non-relatives and is also strongly influenced by ethnicity and culture. Sapountzi-Krepia et al. (2008), state that relatives stay by their patients' bedside for various reasons such as severity of the condition, providing psychological support and family tradition. Familism cannot be left out of socio-cultural factors influencing lay caregiving. This is "a cultural value that refers to strong identification and solidarity of individuals with their family as well as strong normative feeling of allegiance, dedication, reciprocity, and attachment to their family members, both nuclear and extended" (Knight & Sayeh, 2010:7).

In the hospital environment, health care providers are supposed to provide all the health care needs of patients on admission. However, there are certain factors either present or absent in the hospital and in some cases the perception of the public about health professionals' force some people who are not professionals to actively get involve in caring for their loved ones on admission. Some researchers state that family members are forced, unofficially, to stay at patients' bedsides for many hours to assist with their care as a result of nursing staff shortage and specific cultural influences on care provision patterns (Lavdaniti et al., 2011; Stavrou et al., 2014). Some lay caregivers also do not believe their patients are safe in the hospital without their supervision and therefore, the participants offer informal care that reflects specific nursing duties (Sapountzi-Krepia et al., 2008; Stavrou et al., 2014). Sapountzi-Krepia et al. (2008) therefore argue that Greek hospitals 'use' relatives as unpaid labour to compensate for nursing shortage and it is disquieting that usually someone from the hospital staff suggests to the relatives to stay

at the patient's bedside even after visiting hours or to hire a privately paid patient's helper. This implies that the staff considers such a contribution necessary and without the help of these lay caregivers it will be very difficult for professional staff to meet the increasing health needs of patients. Stavrou et al. (2014) identify unsatisfactory care (in quantity) on the part of the nursing staff as one of the reasons why lay caregivers spend time with their sick loved ones.

Tzeng and Yin (2008a) surveyed the roles for and motives of being a visitor to accompany a hospitalised loved one in a Taiwanese hospital and found that their primary motives included, but were not limited to, care being one of their responsibilities, coming to help voluntarily, showing filial piety for their parent, and being afraid that the patient could not obtain appropriate care. These authors were concerned about the positive contributions of lay caregivers without considering the health risk of these caregivers who due to the condition of their loved ones tend to forget about their own health condition and sometimes also become sick after the patient they have been caring for is healed due to opportunistic infections.

Some caregivers also stay in the hospital environment to provide care out of fear for the patient's safety (Aziato & Adejumo, 2014). Some believe that their absence from the hospital environment may cause the patient to die. This is based on the assumption that once a person is sick, he/she becomes vulnerable to death. Lay caregivers may want to spend the 'last moments' with a relation for sentimental relations. Simply, the fear of the unknown influences caregivers to stay in the hospital environment.

Provision of psychological support for the patient and arousal/emotions e.g feelings of sympathy towards the sick which are all personal whether with altruistic or egoistic motives influence lay care giving (Aziato & Adejumo, 2014; Feeney & Collins, 2003). Wolff and Roter (2011) add

that the age of the person, for example very old people need lay caregivers to meet their health needs. Morgan et al. (2014) explain many caregivers described the need to get a better understanding of what was happening and affection for the patient as reasons why some lay caregivers provide care. del-Pino-Casado et al. (2011) also report that giving meaning to life, which includes dignifying, feeling competent and a desire to live in relationships; financial compensation; and a lack of alternatives means of care as the reasons for lay caregiving. Feeney and Collins (2003) indicate that the provision of care for people in an intimate relationship is motivated by a feeling of love, concern and interdependence on each other. He furthered his argument that others also engage in caregiving because they enjoy helping and the social relationship that exists between them.

### **2.3. Forms of care**

Spending time and talking with patients, encouraging patients to take medication, providing assistance with personal hygiene, feeding, making beds, toileting, bathing, and helping to take oral medications are some of the specific care the family members provide for their hospitalised relatives. Lavdaniti et al. (2011), Whitlatch, Schur, Noelker, Ejaz, and Looman (2001) and Tzeng & Yin (2008a) suggest that some visitors provide only their loved one's physiological needs. These are the physical things the patient, due to ill-health, cannot provide for himself or herself. These may include oral and facial care, getting dressed, monitoring the flow of the I.V. fluid, body washing in bed, running of errands, providing a bedpan, washing the hair, transfer activities (bed to wheel chair and vice-versa), transfer of patient to hospital departments (X-rays, laboratory) and help with physical therapy exercises etc (Stavrou et al., 2014).

Analysing the role of lay caregivers, Tzeng & Yin (2008a) surveyed the roles for and motives of being a visitor to accompany a hospitalised loved one in a Taiwanese hospital and found that their primary motives included, but were not limited to, caring being one of their responsibilities, coming to help voluntarily, showing filial piety for their parent, and being afraid that the patient may not obtain appropriate care.

According to Whitlatch et al. (2001) and Sackey (2009) visiting the sick is a form of care and lay caregivers often provide this care. Sackey (2009) further adds that visiting is a form of care that most people overlook but apart from the needed company it provides the sick; it also provides them with the dignity to know that they are thought of.

Wolff and Roter (2011) also suggest that family caregivers provide companionship to their sick loved ones; and logistical assistance is also given as expressed in the provision of transportation and physical assistance (Laidsaar-Powell et al., 2013). In caring for children with complex needs at home, Kirk (2001) finds that in the UK, parents perform complex roles which are purely professional. These include changing tracheotomy tubes, administering intravenous injections and administering parental feeding. Caregivers also provide emotional support, reassurance and advocating for the sick in healthcare decisions in hospital (Feeney & Collins, 2003; Hemsley, Balandin, & Togher, 2008).

In Ghana, Sackey (2009) identifies that family members provide care which can take the form of actual physical care, provision of money and other necessary materials or making arrangements or decisions towards the same purpose while Aziato and Adejumo (2014) add that family members provide emotional care as well.

#### 2.4. Lay Caregivers in Institutional Settings

Hasselkus (1992: 15) writing on caregiver and professional worlds expresses surprise at the active involvement of lay caregivers in health care delivery in the medical setting. As the author states, “the extent of active involvement of family caregivers in what would traditionally be considered physician domain of medical care is unanticipated. It seems clear that while the caregiving emphasis in the home setting was on the everyday social context of the caregiver and the care receiver, in the medical setting, the caregiver’s focus shifts to health care *per se*”. Hasselkus (1992) however, indicates that in the medical setting, the family caregiver serves as the primary resource to the physician for historical information about the patient and is very useful even when the patient was cognitively impaired or *not* cognitively impaired. The caregiver becomes more useful by providing additional information considered useful for the physician and sometimes even suggests the course of treatment to be given to the patient (Glitin, undated). Allen and Ciambrone (2003) call this the advocacy role and the caregiver is also able to influence the physician’s decision regarding diagnosis. Caregivers are said to have shown a sense of commitment to their responsibilities of care towards the patient. However, the caregiver is said to see the physician as a resource from whom guidance regarding patient care could be obtained. Lavdaniti et al. (2011) indicate that in Greek hospitals, the nursing staff assists patients. However, the provision of care by informal caregivers is a common phenomenon. This is because the family has a central role in maintaining the health status of its members and providing informal health care is critical in helping its members to manage illness as well as in assisting in the recovery and rehabilitation process. Family caregivers are also useful in the provision of feedback to evaluate treatment effectiveness, medication management and follow-up with doctor appointments.

From the literature, failure on the part of health professionals to appreciate the contributions of family caregiving expertise and affective work in institutional care settings is a potential source of conflict. Ward-Griffin and McKeever (2000) and many other researchers have repeatedly reported that family caregivers develop collaborative relationships with health professionals in order to avoid or decrease such conflicts. However, Blum and Sherman (2010:244) indicate that at the hospitals, “the family caregivers were often shut out by the rigid visiting hours, clinical language they did not understand and a sense that their toil was not adequate to the task”. Oliver et al. (2013) also add that health professionals do not take the well-being of the lay caregivers into consideration. To Laitinen (1993) many relatives seek to increase their participation in patient care but are prevented from doing so by the obstructive attitude of nurses.

Another area of conflict between the health professionals and lay caregivers are the differences in priorities and perspectives of the two parties (Allen and Ciambrone, 2003). Whereas lay caregivers are concerned about the care of their loved ones, health professionals on the other hand are concerned about all patients on the ward. Claymana, Roterb, Wissowc, and Bandeen-Roched (2005) indicate that patients’ caregivers help in clarifying and expanding patient’s history to the medical practitioner and also help in facilitating the understanding and involvement of patients in the medical process. Writing on the information needs of caregivers of older adults with chronic health conditions, Washington, Meadows, Elliot and Koopman (2011) indicate that caregivers need both general and specific information. Whereas the general information refers to the knowledge regarding the etiology, diagnosis and treatment given to their loved ones, the specific information is focused on the individual needs of caregivers themselves.



Ugochukwo et al. (2013) state that even though it is recognized that the family plays a role in the care of ill family members around the world, in many low-resourced sub-Saharan African countries, care in hospitals, including food and medication, is supplied by the family and a family member stays with the patient most of the time. These family members also render certain key services which are supposed to be the preserve of the health professionals to their sick loved ones. To them, this may be by default rather than design. It could be deduced that whereas lay caregiving in some countries is a choice, in some sub-Saharan African countries, it is compulsory or a must. Ugochukwo et al. (2013) however, did not identify the specific countries where it is made compulsory for lay caregivers' involvement in the care for the hospitalised.

## **2.5. The Relationship between Caregivers and Health Professionals**

It appears that family caregivers occupy an ambiguous position in relation to health care professionals, who tend to view them as both the problem and the solution to the care of the ill family member (Twigg & Atkin, 1994). Some research findings indicate that caregivers view the relationship between them and the physician as one between two practitioners rather than between a patient and a doctor while the physician also views the caregiver as a substitute for the patient doing what the patient is supposed to be doing. This refers to situations where some caregivers for example, want to provide answers to questions on behalf of the patients. Physicians sometimes also view the caregiver as a second patient who has health problems and therefore needs medical care and very rarely do they see the caregiver as a partner in care with whom to negotiate and exchange knowledge. Hasselkus (1992) therefore identifies three dimensions in this regard. While the caregiver views herself first as a practitioner, patient substitute and a second patient, the physician on the other hand views the caregiver first as a patient substitute, second patient and practitioner. Hasselkus (1992:75) further explains "the

caregivers have moved far beyond viewing themselves merely as founts of medical information and historical details. With their long term experience in monitoring symptoms, making treatment adjustments, linking causes with effects and otherwise acting as primary caregivers, these caregivers retain this view of self as primary health care provider in the clinic setting. To the caregiver, the physician is a resource from whom to obtain guidance or against whom to bounce off their most recent diagnoses and treatment suggestions. The relationship between the family caregiver and the medical doctor is viewed by the caregivers as one between two practitioners and is, thus, very different from a relationship between doctor and patient". Blum and Sherman (2010) for example state that the nurse, the caregiver, and the cared-for are a "three-fold cord that is not quickly broken.

To Kirk (2001), the relationship that develops between these caregivers and the health professionals is normally marked by conflict rather than partnership. According to Winefield and Burnett (1996), this conflict is caused by what they call "system-wide inadequacies in resources" possibly on the part of the institution on one hand and on the other, the attitude of the health professional. They therefore suggest that the health professional and the lay caregivers should see themselves as "co-therapists" in the health delivery system. Ward-Griffin & McKeever (2000:91) also report that, "conflicts arise when health professionals fail to recognize family caregivers' expertise, when roles overlap, when roles are defined rigidly or when professional expectations of family caregivers are contradictory". To them it appears that family caregivers occupy an ambiguous position in relation to health care professionals, who tend to view them as both the problem and the solution to the care of the ill family member. Ward-Griffin & McKeever (2000) furthered their argument that the failure of health professionals to value family

caregiving expertise and affective work in institutional care settings has been reported as one source of conflict in formal-informal caregiver relationships.

Ward-Griffin & McKeever (2000) identify four distinct, yet interconnected types of relationships between nurses and family caregivers. These are: nurse-helper, worker-worker, manager-worker, and nurse-patient. With reference to nurse-helper relationship, nurses provide and coordinate the majority of care, while lay caregivers assume supportive roles to the nurses. Both the health professional and lay caregiver see themselves as co-workers under the worker-worker relationship. The health professional believes that the lay caregiver has some experience or expertise which needs to be tapped for a holistic care delivery hence; they need to work as a team. Further, as more experience was gained by the lay caregiver from the delegation of professional care to him or her by the professional, the professional turns to supervise or monitor the caregiver's roles rather than taking an active part in care. This relationship is described as manager-worker. With nurse-patient relationship, the lay caregiver is seen by the health professional as someone in need of care in their own right, especially those women who were elderly or who had chronic health conditions and as a result the caregiver also becomes the nurses' patient.

## **2.6. Impact of Lay Caregiving on the Patient**

Neil, Twibell, and Harris (2010) emphasise that nurses need to embrace family presence, even during crises, as a way to keep families connected and to improve patients' clinical outcomes during hospital stay and after being discharged. This is because the presence of the family members provides an opportunity to family members to monitor the condition of health and also provide the needed care for their sick relative. Similarly, Remen (2006) indicates that family

involvement in bedside inpatient care is increasingly being emphasized as a means to provide safer and error-free bedside care. This is due to the fact that family members pay attention to only their sick relative and will therefore pay attention to certain insignificant but important things or signs that will help the professional health care giver. The professional health caregiver who is overwhelmed with a large number of patients may not pay attention to insignificant but important signs the patient may exhibit. Sapountzi-Krepia et al. (2006) also indicate that, lay caregivers' involvement in care for the hospitalised results in an increase in survival rate of care recipients (patients).

Herath (2014) study on factors leading to re-hospitalisation and the care provided revealed that family interventions were very much evident and proved to be very effective in reducing the impact of the illness on the patient and family. To Wolff and Roter (2011), when family members are involved in interpersonal health care processes, it leads to the improvement in the quality of patients' health care as they, for example, motivate patients to keep to the prescriptions given them by the health professionals and also help in providing certain vital information about the patient to the physician. Parkes (1982) also indicates that social support provided by lay caregivers help in the reduction of stress on the patient and as a result speeds up the healing or recovery process. Similarly, Abraham and Shanley (1992) report that informational care provided by lay caregivers is important for the psychological well-being and minimisation of anxiety on the patient. However, with regard to the role of lay caregivers and health professionals, patients feel they have not been well involved in decisions concerning their care (Toscan, Mairs, Hinton, Stolee, and Team 2012). The positive impact of lay caregiving on the patient's therapeutic process cannot be underestimated.

## **2.7. Positive Impact of Lay Caregiving on Caregiver and the Community**

Fulfilling social obligation to the sick has been identified as one of the positive impact of lay care giving on the caregiver. Goodhead and McDonald (2007) state that, most caregivers are happy about what they do and do it with all joy. However, the quality of the relationship between the caregiver and the care recipient actually influences the feeling of the caregiver. Other benefits of lay caregiving include inexpensive care and gaining experience in care (Sapountzi-Krepia et al., 2006). Not only do the caregivers get experience in managing the present health condition of their patients but also gaining experience to manage other health problem (Hynes, Stokes, & McCarron, 2012). Caregiving also become less expensive for the government and patient because what should have been paid for if they were done by a health professional is being done by a family member and nobody pays for it.

In Ghana, there is not much documented data that indicate the benefit the state and insurance companies derive from the use of lay caregivers in care provision at the hospital. However, Nortey, Aryeetey, Aikins, Amendah, and Nonvignon (2017) report that caregivers spend an average of 219.5 hours and a total of 17, 900 hours on patients monthly. Costing this, they indicate that the average cost of family caregiving is around US\$186.18 per month while the total cost for a month is estimated at S\$14,568.03. In the developed countries, the rationale for the use of lay caregivers is based on the premise of reducing cost to government and insurance companies as an increase of just one hour of additional care by a registered nurse per day at \$40 per hour in California for example was reported would increase costs by \$4,000 per day and \$1.4 million dollars annually. Hirst (2002:1) reports that “the market value, or replacement cost of unpaid care provided by family members and friends to ill and disabled adults in the United States of America was estimated to be \$196 billion in 1997. The economic value of informal

caregiving in Britain is reported to be around £34 billion per year, although the methodologies used to produce such estimates are contested”. As a result, supporting informal caregivers in their role of caring for their sick relations is of high concern on the public policy agendas of many developed countries. Conflicts therefore arise when health professionals fail to recognise family caregivers’ expertise and or their expectations of the family caregivers are contradictory. Sometimes, roles overlap or rigidity of roles also cause conflict between the two parties (Ward-Griffin & McKeever, 2000).

## **2.8. Challenges of Lay Caregivers**

Even though literature reveals the positive impact of care on the lay caregivers, they are also confronted with some challenges. Family caregivers suffer physically, emotionally, financially and socially and this sometimes makes them pay less attention to their own needs. Some caregivers express negative emotions as anger, depression and anxiety (Wacharasin & Homchampa, 2008). Financially, the time spent in giving care may result in job loss and/or loss of wages. The social life of the lay caregiver is also compromised in most cases as the desire to see the sick become well takes precedence over their entire life. The work of the lay caregiver is described as all-embracing as they are seen performing many care activities. Writing on the experience of caregivers, Oliver et al (2013:847) state: “the home of a dying patient has been compared with a hospital unit in which informal caregivers are expected to manage all aspects of patient care; those lacking formal education are left anxious, exhausted, and burdened”. Whitlatch et al. (2001) also indicate that lay caregivers also experience stress as a result of their caregiving activities.

Furthermore, lack of knowledge as to what to do and sleep deprivation are also identified as problems facing the lay caregiver (Wacharasin & Homchampa, 2008). Goodhead & McDonald,

(2007), also identified systemic barriers limiting caregivers' access to services. These may include health professionals failing to recognise caregivers as patients in their own right.

Establishing a relationship between income and caregiving burden, Andrén and Elmståhl (2007) indicate that caregivers with low income status experience more caregiving burdens than caregivers with high income levels. Further, caregivers who live away from their homeland or far from relatives experience a higher burden just as urban dwellers experience more burdens than rural dwellers. Andrén and Elmståhl (2007) further indicate that caregiving has both a direct and an indirect cost to the caregiver. The direct costs are those involving the provision of personal care, pharmaceuticals, medical consultations and physician services, among others while indirect costs comprise loss of earnings by family caregiver since they have to relinquish employment and value of time lost from caring activities. Social isolation, loss of sleep, energy and mobility were also identified.

Glitin (undated) indicates that the economic well-being and employment status of caregivers are affected in that the participation of women in the workforce is changing. However, she did not explain further how it is drastically changing. In their study, Hynes et al. (2012) indicate that lay caregivers expressed frustration concerning the fact that fuller explanations were not given them by health professionals about the disease trajectory and management and this often results in fear, isolation and anxiety. Travelling to and from the hospital as a result of the hospitalisation of a loved one is also seen as an added physical and emotional burden on the caregiver (Morgan et al., 2014). Lay caregivers experience the challenge of getting access to information about the disease condition, unclear roles and responsibilities as health professionals become inconsistent in recognising their roles (Toscan et al., 2012).

In their study on the challenges facing informal caregivers in Uganda, Emanuel et al. (2008) identify financial assistance, pressure to stop attending school, take embarrassing jobs, transportation difficulty from home to care centre, having to work fewer hours or stop work entirely due to time and energy needed to take care of the sick as some challenges LCs face. However, informal caregivers mentioned the ill conditions of their loved ones as most worrying. Even though caregivers consider hiring someone to take care of their sick in order to have more time to work, have time for themselves and other close family members, they find the cost of such services as the greatest obstacle.

Ae-Ngibise et al. (2015) reports that in Ghana, lay caregivers for people living with mental disorders are confronted with challenges of emotional distress and stigma as they are all the time found thinking about their sick relatives. Lay caregivers are also faced with economic burdens and non-availability of support for them. This notwithstanding there is so much burdens on their time as caregiving demands spending most part of their time with the sick. Klopper, van Dyk, and Pretorius (2015) also reports lack of social support for lay caregivers in Namibia.

## **2.9. Nurse - Patient Ratio**

From the literature reviewed so far, shortage of staff came out as one of the major institutional factors accounting for the phenomenon under study. Both professionals and non-professional caregivers cited inadequate staff to cater for the needs of the large numbers of in-patients at the wards as the major factor influencing lay caregivers to provide care in the hospital environment. In Ghana, there is no current literature on nurse-patient ratio. However, the Ghanaian Times (2014) reports that the nurse patient ratio in 2012 was 1:1,251. Quaicoe-Duho (2015) also reports that the nurse population ratio improved by 20 per cent over 2012 but did not meet the



programme of work for the 2013 target of 1 (one) nurse to 800 citizens. However, Oulton (2006) indicates that global nursing shortage is having negative effects on health systems around the world and since 2002; nursing shortage has been termed a global crisis. There was therefore the need to find out what should have been the ideal as far as nurse-patient ratio is concerned.

Literature reviewed so far on nurse-patient ratio does not give any standardised or universally acceptable number when it comes to nurse-patient ratio. Tevington (2011) reports that the mandatory nurse-patient ratio law was passed in California in 1999, with the passage of the California Assembly Bill 394, which mandated minimum, specific, and numerical nurse-patient ratios in hospitals. Tevington (2011:265) adds that “the final bill, which was to be implemented in 2004, mandated a nurse-patient ratio of 1:5 in medical surgical units (smaller ratios) were assigned to specialty units”. According to Wise, Fry, Duffield, Roche, and Buchanan (2015), in Australia, the State of Victoria formulates its ratio on the number of beds per a nurse rather than patients; as a result, three (3) beds are assigned to one nurse in addition to one dedicated “triage nurse” for the highest level emergency departments while in California, the nurse patient ratio is one nurse to four (4) patients in the emergency ward. However, it must be noted that, these three beds per nurse is not a standardised one as according to the report by Wise et al. (2015), the bed-nurse ratio changes from one level to another based on the criteria they use. As a result, at some levels there are four beds to a nurse while at others there are five beds to a nurse. This is the State of Victoria’s policy on nurse patient ratio in the emergency department. Similarly, in California, Tevington (2011) reports that the variations in the nurse-patient ratio is influenced by the condition of the patient. However, the small nurse to patient care plan came with a cost as more nursing hands would be needed. As a result, more funds will also be needed to be able to pay them. Due to financial reasons, California Governor, Arnold Schwarzenegger sought to delay

this bill until 2008. As Welton (2007) reports, another problem related to mandatory staffing ratios is the cost associated with hiring new nurses. For example, “consider a medium-size hospital that has on average 100 adult medical-surgical patients. An increase of just one hour of additional care by a registered nurse per day at \$40 per hour would increase costs by \$4,000 per day and \$1.4 million dollars annually”.

The benefit of a good nurse-patient ratio as found in literature is believed to increase patient safety, patient satisfaction and quality of care and also reduce nurse burnout and turnover. However, Welton (2007) suggests that since nurse-patient ratio may result in increased overall costs of care with no guarantees for improvement in quality or positive outcomes of hospitalisation, an alternative plan for better care delivery must be considered and suggests “Nursing Intensity Billing”. By this, the intensity of nursing care need for a given patient should be considered rather than a mandatory nurse-patient ratio. Washington is also cited to have adopted a “safe staffing plans” rather than a mandatory nurse-to-patient staffing ratios.

## **2.10. Role negotiation**

Negotiation according to Griffin and Moorhead (2007: 407) “is the process in which two or more parties (people or groups) reach an agreement on an issue even though they have preferences regarding that issue”. This definition has given a broad framework within which most forms of negotiations that occur at the work place or within organisations can be fixed. It implies that negotiations can take place in different forms either between two individuals, between an individual and organization or group, or between two groups or organizations. During negotiations therefore, each party tries to influence the other in order to get the best outcome. Lay caregivers most often will enter into negotiations with the health professionals on individual

basis that is nurse and caregiver level rather than individual (caregiver) and group or organizational level (hospital). Reeves, Timmons, and Dampier (2006) also define negotiated care' as the process of nurses discussing with parents the level of care that they wish to be responsible for while in hospital, and discussing plans for the child's care'. This implies that formal agreement is reached between parents in this case, lay caregivers and health professionals on the contribution that each could make towards care delivery for the sick. In the UK for example, McCann et al. (2008) indicate that the key emphasis in negotiation of care between lay caregivers and the health professionals is on mutual discussion which does not only clarify the expectations and role delineation of each party, but which also involves active role negotiation and decision making. They therefore developed "the negotiated care tool" which provides the opportunities for nurses and parents to ask questions, and to negotiate the extent to which they wanted to be involved in their care of the child. The negotiated care tool is only to make communication between the caregiver and the health professional very effective but does not provide any theory or model within which negotiation in general occurs between these caregivers. Negotiation of care should therefore be seen as a serious business between the parties involved and a consensus or agreement is reached before actions are taken and may need some formal processes to be recognized as such and will be influenced by certain factors. This formal agreement on care is not the case for Ghana. In Ghana, lay caregivers' involvement is rather more informal in nature where both health professionals and lay caregivers turn to be playing different roles as and when the need arises.

Griffin and Moorhead (2007) have identified four approaches to negotiation within the work environment. These approaches are simply the factors influencing the negotiation process and they include individual differences, situational characteristics, game theory and cognitive

approaches. Individual differences approach is based on the assumption that personal traits such as demographic characteristics such as age, gender, race; and personality variables like ability to take risks and tolerance influence the negotiation process

Situational characteristics refer to the context within which negotiation takes place. According to Griffin and Moorhead (2007) it may include the nature of communication between the parties involved in the negotiation, the potential outcome of the negotiation, the level of power each party possesses and the length of time for negotiation among others. The authors however indicate that many situational characteristics are external to the negotiators and are often beyond their control.

The game theorists suggest that every alternative and outcome must be carefully analysed to reflect the preferences for whichever outcome to be considered. This approach also makes it possible for parties involved in negotiation to make choices and the outcome of every step taken can be predicted. This is because the approach requires that every alternative and outcome be analysed with possibilities and numerical outcomes reflecting the preferences for each outcome. However, the theory assumes that parties in negotiation can make rational decisions at all times.

According to Griffin and Moorhead (2007) the cognitive approach to negotiation is based on the assumption that negotiators can depart from perfect rationality during the process and it tries to predict how and when negotiators will make these departures. This fourth approach is found to be very useful in most negotiation processes.

Reck and Long (1985) also identify the win-win approach to negotiation. This approach is said to be useful in carrying out difficult negotiations. To Reck and Long (1985), the win-win approach does not treat negotiation as a game in which there are winners and losers. Instead, it approaches

negotiation as an opportunity for each side to be a winner. That is for each side to get what it wants from the agreement. Simply, as far as this approach is concerned, both parties want to have their needs satisfied. The approach further assumes that both parties work together to find ways that will satisfy them simultaneously.

Ward-Griffin & McKeever (2000) state that in order to keep public costs down, nurses use three major strategies in negotiating care with family caregivers and one of such strategies is delegating as much care as possible to the family caregiver. The second strategy is gradually decreasing the frequency and range of care provided to the sick and the third is advising caregivers to access other less expensive community services. Also, negotiation of care with family caregivers was identified in three distinct stages in evolving relationships. These are naive trusting, disenchantment and guarded alliance. The naive trusting stage in the negotiation process is used to describe the relationship that develops between the two caregivers at the early stage of their encounter where the lay caregiver expresses belief and trust in the professional as having his/her interest at hand. The second stage, which is disenchantment, occurs when the health professional behaves contrary to the expectation of the lay caregiver and this stage is characterised by mistrust which may result in withholding information or providing insensitive care. “The final stage in the development of a negotiation relationship is the guarded alliance. This was conceptualised as a relationship between professionals and family caregivers based on four different styles of trust in the parties. These styles were hero worship (trust of one individual professional), resignation (feelings of hopelessness), consumerism (focus on services needed rather than relationships) and team playing (both perspectives are equally valued)” (Ward-Griffin & McKeever, 2000: 92).

Allen (2000) indicate that negotiating expertise in the hospital setting is underpinned by some important tensions one of which is the difficulty of professionals to reconcile the contemporary ideology of participatory practice which calls for lay involvement in the care delivery system and a claim to professional status and expertise by hospital staff. Although nurses recognise informal caregivers as valuable resources, they find it difficult to draw on their knowledge in a way that does not undermine their sense of professional competence. This is due to the fact that there is an asymmetrical, super and subordinate relationship in terms of power between the professional and the lay caregiver. The professional, because of the training he went through feels he knows it all and therefore sharing that power with the lay caregiver becomes a challenge. Allen also indicates that since the knowledge or practice the lay caregiver developed at home is at variance with what is practiced at the hospital, tension develops.

Allen (2000) further reports that professionals are able to negotiate their roles with caregivers through staging which refers to the use of self-serving strategies by which individuals and groups are able to control the context in which negotiations occur and compromise is one of such strategies. Another area of negotiation between caregivers and professionals is the standard of care. Allen indicates that care in the home is more flexible as activities are organised to meet specific needs of the patients. However, care in the hospital setting is not all that easy. Also care activities performed by a single caregiver at home are done by different people in a hospital. Furthermore, care at home is based on the affective relationship between the caregiver and care recipient while that of the hospital is based on contract. According to the author, the affective element of care is important in the understanding of the negotiation context as negotiation between the professional and lay caregivers occurs in the context of unequal power.

Writing on the topic “Negotiating lay and professional roles in the care of children with complex health care needs”, Kirk (2001) indicates that parents of such children intimated that their initial involvement in providing care for their children was not “subject to negotiation with professionals”. However, their involvement was greatly influenced by their feelings of obligations, the absence of alternatives to parental care in the community and their strong quest to have their children at home. On the other side, Kirk (2001:595) states “The professionals participating in the study had concerns over whether this group of parents was given a choice in accepting responsibility and the degree of choice they could exercise in the face of professional power”. Hayes and Kjioux (1984) for example, state that, parents and professionals may have different role expectations of one another’s involvement in care, and this may be different and possibly conflicting perceptions of each other’s role. The relationship that develops between these caregivers and the health professionals is normally marked by conflict rather than partnership. Darbyshire (1994) reports that in some cases, caregivers are forced to take responsibility of care and negotiation is influenced by the social environment and in particular the balance of power (Trnobranski, 1994). However, power is not equally shared between lay caregivers and professionals in the hospital context. There is super and sub-ordinate relationship between the two where the professional seems to know it all. As Kirks (2001: 597) rightly put it “professionals feel that it could be difficult for parents to counter professional expectations of parental roles in the hospital context because of power asymmetries”. The level of involvement is, however, influenced by the professionals’ perceived ability of the caregiver in care giving. McCann et al. (2008) state that parental involvement in the care of their sick child at the hospital is often tolerated, rather than actively encouraged. Kirks was however, not able to develop a

clear model for role negotiation between the health professionals and the lay caregivers who are the parents of the children involved in her study.

It can be gathered from the literature reviewed that lay caregivers provide different forms of support to the sick. Provision of such supports is influenced by different motives which may be egoistic, altruistic or as a cultural demand. However, the level of involvement in care differs from country to country. Whereas much recognition is given to lay caregivers in the developed countries, little recognition is given in developing countries such as Ghana. Also, there is limited number of literature on how lay caregivers negotiate their roles with the health professionals in the hospital setting. It is this gap that this study intends to fill. The next section focuses on the theoretical framework of the study.

## **2.11. Theoretical Framework**

Myrdal (1968) has argued that health has both intrinsic and instrumental value: it is desired for its own sake and more importantly, it is the wheel around which a society's progress and survival revolve. Thus the desire to keep members healthy is of a great concern not only to the family, but also to the society at large. From the functionalist perspective therefore, a break or malfunction in one part of the system disrupts the normal functioning of the whole system. A threat to an individual in whatever form but most especially by severe illness is considered as a threat to the existence of the whole system. Members of the family must therefore employ all the necessary control mechanisms to rectify the disequilibrium caused by the ill-health. One of the functions of the family as a social system is therefore, to keep its members in good working condition, relieving them of anxiety by providing encouragement and caring for their physical ailments. The basic idea behind helping the sick person to get well is to keep him or her active so as to



enable him/her contribute his or her quota to the normal functioning of the system. There are several competing and complementary theories for this study; however, at the heart of this work are the social exchange and cultural care theories.

The social exchange theory is relevant for this study because it describes the various reasons and forms of exchange that take place within the social system. It must be noted that in this, exchange does not only take place between the sick and the family caregivers but also between the professional and family caregivers.

According to Emerson (1976) even though the founding fathers of social exchange theory: (George Homans, John Thibaut, Harold Kelley and Peter Blau) differ in their orientation, the theorists agree that social exchange involves a series of interactions that generate obligations. These interactions are however interdependent and contingent on the actions of the parties involved. These theorists also believe that social behavior is influenced by the rational calculation of an exchange of rewards and costs. Homans (1974) for example indicates that in exchange relation, human behaviour is influenced by five propositions. These are the success, stimulus, value, rationality and deprivation-satiation propositions. The success proposition states that when an action undertaken by a person brings more rewards, the most likely it is that, that action will be repeated while the stimulus proposition indicates that when a past action of an individual under a particular condition is rewarded, it is highly likely for the individual to repeat the action under similar conditions. Homan furthered his argument that the more valuable the result of an action is to a person, the more likely is the person to engage in such actions. The rationality proposition indicates that when an individual in confronted with a choice between alternatives, the individual will choose the alternative perceived to have greater result and which is of value to him/her. The deprivation-satiation proposition, however, indicates that “the more

often in the recent past a person has received a particular reward, the less valuable any further unit of that reward becomes for him” (Homans 1974:29).

All the above propositions (except deprivation-satiation) have great influence on the behaviour of lay caregivers (LC) within the hospital setting. Most caregivers see human life as more valuable than anything and engaging in actions which will preserve human life is most rewarding in life. Furthermore, LC’s find caring more profitable to themselves and their patients than any alternative action. However, as Cropanzano and Mitchell (2005: 876-7) indicate, an exchange relationship is influenced by rules of reciprocity. They identified three types of reciprocity: (a) reciprocity as a moral norm; (b) reciprocity as a folk belief and (c) reciprocity as a transactional pattern of interdependent exchanges. They explain that as a norm, reciprocity is considered a cultural requirement and non-conformity is punishable. Regarding folk belief, they indicate that it is a cultural expectation that people must get what they deserve. To them “the key difference between a norm and a folk belief is that norms involve a quality that philosophers sometimes term *ought*” (Cropanzano and Mitchell 2005:877). For interdependent exchanges, they report that the action of one party leads to the response of the other. Helping acts may and are greatly influenced by societal norms. The cultural and social norms which are the acceptable behaviours in every given society influence human behavior greatly. Social and cultural norms such as doing good in return for a favour one has received from someone or for something good that someone has done such as showing love or assisting those in need, fulfilling moral obligations towards close blood relations and general social responsibility towards one another in the society are some but few of the social and cultural reasons for assisting the sick. The forms of reciprocity identified by Cropanzano and Mitchell (2005) are not left out of the factors influencing lay caregivers.

Similarly, Leininger's (1991) cultural care theory indicates that cultural and social structure factors of health consumers are important in understanding caring or health-seeking behaviours. The social structure factors of clients include "religion (spirituality), kinship (social ties), politics, legal issues, education, economics, technology, political factors, philosophy of life and cultural beliefs and values with gender and class differences" (Leininger 2008:7). It is believed that the social structure directly or indirectly influences health and well-being and must be understood by care providers. Understanding the worldview of a people is therefore at the heart of the culture care theory.

Closely related to Cropanzano and Mitchell's reciprocity and Homans' success proposition is Franzoi's, (2000) explanation of helping behaviour. Franzoi (2000) explains altruism as a helping act motivated primarily by an anticipation of its positive consequences for another individual. This assertion by Franzoi may be true to some extent. However, every human action has both manifest and latent functions and as a result, the egoistic theorist also states that people help others for their own personal gains. Caring for the sick is motivated by both altruistic and egoistic reasons.

From the altruistic point of view, helping an unconscious or seriously ill patient is to assist such a patient to receive care that he/she could not have provided for himself or herself which in this case could facilitate the survival of such an individual. This could be the manifest motive. This act is motivated by arousal and emotions such as feelings of sympathy. As a result, altruistic motivations for helping involve benefiting another as an end in itself, that is, benefiting others is an ultimate goal in its own right and any associated self-benefits are unintended consequences (Feeney & Collins, 2003). Therefore, the latent motive could be that such act is influenced by the

fact that the loss of the patient's life may affect the caregiver economically or emotionally and as a result, every effort must be made to sustain life. In connection with this, Parsons' (1951) sick-role theory suggests that the following expectations apply to the sick person to a greater or lesser degree depending on the severity of his illness: that he avoids obligations which may worsen his condition; that he accepts the idea that he needs help; that he desires to get "well" and that he seeks technically competent help in getting well.

Illness is thus regarded a legitimate reason for withdrawing from normal role expectation if the various obligations of the sick-role are accepted. The sick individuals are not held responsible for their conditions and are excused from their normal role expectations if they view the state of being ill as undesirable and agree to take remedial action such as seeking competent medical care. The expectations of the sick-role concept are the expected behavior of the one who is sick, but it is also known that rates of help seeking vary independently of medical indication. Not all people conform equally well to what is expected. Economic and other socio-demographic factors, cultural background or kinsfolk influence and insufficient knowledge of available sources of care, often prevent rational behaviour though people realise what it is.

Indeed, decisions about health may be weighed in relation to family and work needs, social and cultural demands on a person's efforts, concerns and finances. However, whichever decision holds sway must form part of the repertoire of the prevailing social system. One of the prime tasks of this system therefore is to ward off the threat (ill-health) and whenever it occurs to marshal all resources to combat it. It is in response to this that lay people are now seen in the environment of professionals to provide care.

The egoistic caregiver may be helping the sick because of some expectation of material reward to be received at the end of the service because all things being equal, people who are wealthy tend to receive better attention from their family members when they get sick than the poor. Also, a caregiver may want to be seen as a “good” person in the eyes of the society and will therefore offer help to the sick.

Social network and support theorists share similar views with the social exchange theorist in that various forms of exchange occur in social network and support relationships. The impact of social network and social support on the health of the individual cannot be underestimated. As Durkheim (1951) argues in his *Suicide*, the individual’s association with others especially the degree of integration has great impact on one’s health or the tendency to commit suicide. Social network of an individual is the cluster of social relations in which the individual finds himself or herself. According to Williams and Durrance (2008) social network analysis cannot be studied using any single network relationship in isolation from the general network of which it is a part. They argued that a dyad, which is a relationship between two individuals, even though a building block of every network is itself conditioned by the network. Williams and Durrance (2008) report that the relationships that exist between members of a social network is based on the flow of resources which could be emotional, financial, social and information support and even time. This flow of resources is at the heart of social exchange theory. Reblin and Uchino (2008) indicate that people with high quantity and quality of social network have decreased rate of mortality than those with low level of social network.

Social support refers to how members of social network help each other to cope with stressful situations. In connection with this, House (1981) identifies four main types of social support which are emotional, instrumental, appraisal and informational supports. House indicates that

emotional support deals with sharing of life experiences with one another which can be in the form of caring and empathy while instrumental support has to do with assisting a needy person with material things which help the individual directly. For informational and appraisal supports, the author explains that the former has to do with provision of vital information which can be used in solving a problem while the latter deals with giving information necessary for “self-evaluation” which could be in the form of a feedback or affirmation of an idea. As Mattson, (2011: 184) indicates “social support could be actual support that a person receives in the form of what is said, what is given and what is done for the individual. Perceived support refers to the individual’s belief that support is available and is considered positive and negative. Perceived support is sometimes more important than actual”. These forms of support were evident in the expressions of patients and lay caregivers during the field work. Social network and social supports theories are therefore, very important for the understanding of lay caregivers’ involvement in care at the hospital since involvement is influenced by the provision of such vital supports for the sick.

The significance of studying the interface between the health professional and lay caregiver in the hospital milieu cannot be better understood without making reference to Max Weber’s bureaucracy. Max Weber is credited with the theory of bureaucracy (Appelrouth & Edles, 2008; Coser, 2010; Mulder, 2017). Weber believed that bureaucracy is a management tool and the most efficient way to run any organisation especially large formal organisations. As a management tool, bureaucracy functions with six characteristics of division of labour based on specialization, hierarchy of authority, rules and requirements, formal selection of employee based on technical competence, impersonal relationships and the use of written documents. Briefly explained, work is divided among large numbers of workers based on specialisation or what the worker can do

best and as a result, workers are not expected to go beyond their specific task and take on the task of others. Lay involvement to the extent of performing certain professional task is prohibited in bureaucracy. Hierarchy of authority is essential in bureaucracy and it deals with the various ranks or statuses each worker occupies in the organisation and the hospital is one of such organisations that depend greatly on hierarchy of authority. As shown in the organisational structure of KCH, lay caregivers do not occupy any status in the hospital. Their presence therefore is a deviation from the norm. In bureaucracy, rules and requirements are observed strictly to ensure uniformity in the work environment. Technical competence of the individual is the main criterion for employment or recruitment and as a result, lay caregivers do not fit into bureaucracy. As far as the development of relationships among workers are concerned, official rules are followed hence relationships are impersonal as official views are detached from personal emotions. All organisational decisions, actions and rules are written down to ensure continuity in administration. However, bureaucracy has its dysfunctions.

According Kreitner and Kinicki (2006), every organization is a bureaucracy to some extent and in terms of ideal metaphor, a bureaucracy should run like a well-oiled machine and its members should perform with precision of a polished military unit. However, practical and ethical problems arise when bureaucratic characteristics become extreme or dysfunctional. This may be partly responsible for lay involvement in professional health care delivery in hospitals.

From the foregoing discussions, it may be concluded that lay caregivers' involvement in professional health care delivery is rooted in social exchange. This exchange is influenced by the culture of the people and the perceived reward to be received at the end of such actions. Societal





health professionals and lay caregivers adopt certain strategies to provide the needed care for the patients. As Griffin and Moorhead (2007) indicate, many situational characteristics that influence negotiation are external to the negotiators and are often beyond their control. From the diagram, shortage of health professionals and severity of patient's conditions which influence lay caregiver's involvement in care at the hospital are external to and beyond control of both the health professionals and the lay caregivers. While both the HPs and LCs are influenced by situational factors of severity of patient's condition and shortage of staff, the LC is further influenced by cultural values of moral obligation, reciprocity and care as a tradition, fear of death, religious reasons and value of human life. The HPs are also influenced by their professional obligation to provide care. Whereas the HPs provide mainly medical care needs, LCs on the other hand provide emotional, financial and physical care needs for the patient. In order to provide these supports, these caregivers enter into a compromised relationship based on mutually-accepted win-win approach. The LCs are involved in care through formal and informal strategies while the HP performs his/her formal professional roles. Formally, LCs are told to stay behind to assist with care while informally, LCs get involved through their own volition. Health professionals educate the LCs on what to do and how to do it to get them formally involved. There is therefore information flow between these caregivers as LCs also report on the conditions of their patients to the HPs. The outcome of this involvement is that patients' personal and medical care needs are met and health care is delivered. Leininger (2008:2) therefore reports that "there can be no curing without caring but caring can exist without curing."

Borrowing from the social exchange theorists and Griffin and Moorhead's (2007) situational characteristics, conclusion may be drawn that the interface between the health professional and lay caregiver in this study is influenced by situational demand or urgency of need. The

theoretical framework also provides the foundation for empirical analysis. The next chapter focuses on the methodological issues of the study

## **CHAPTER THREE**

### **METHODOLOGY**

#### **3.0 Introduction**

The context in which an event occurs is very important in understanding the event. In the light of this, it is very prudent to give a brief background of the study area. This chapter therefore begins with a brief background of the study area. The rest of this chapter, therefore, discusses the procedures and techniques employed by the researcher to collect the data for this study. It focuses on the field experiences of the researcher paying attention to the methodological difficulties and factors which influenced the data collection process. The chapter also discusses the research design, target population, recruitment of participants, their number and data collection approaches and instrument used. Reliability and validity of the study, pilot study and data sources, data handling as well as the ethical issues encountered during the field study are also discussed.

#### **3.1. The Study Area**

The Eastern Regional Hospital also known as Koforidua Central Hospital was established in 1926 to meet the health needs of the people in the New Juabeng Municipality and its environs. It was later upgraded to the status of a secondary level referral center for the entire Eastern Region with a population of 2.6 million. The 340 bed-capacity hospital serves as a referral center for the twenty-six (26) districts hospitals as well as Christian Health Association of Ghana (CHAG) and private facilities in the Region.

There have been only two major structural additions since its establishment 91 years ago. The first was in 1972 when an administration block, dental unit, laboratory department, adult OPD with medical records, internal medicine, children, surgical and maternity wards with theatre were added. In 1988, catering, main theatre, x-ray, laundry and mortuary departments were also included. There has been no major rehabilitation or major additional structures since then. However, the hospital benefitted from the 2013 Government re-tooling programme with the establishment of a CT scan center, mammogram and fully equipped neonatal and adult intensive care units.

The administration department with a social welfare unit caters for the needs of the poor and the needy. The hospital also offers the following specialised services: internal medicine including anti-retroviral therapy, pediatrics, surgery, medicine, dental, ophthalmology, physiotherapy, ear, nose and throat, pharmacy, laboratory, x-ray, ultrasound, catering and hospitality, laundry, mortuary and primary healthcare services.

As a secondary referral hospital, it also serves as an institution for training medical doctors, clinical pharmacists, intern pharmacists and other health staff including biomedical scientists. It records an average daily outpatient attendance of seven hundred (700). It also has a Reference Laboratory and eight (8) satellite pharmacies strategically located within the hospital.

The two adult medical wards (male/female) which were selected for the study have different bed capacities. The female ward which is bigger than the male ward is a forty -two bed capacity ward with seven cubicles/rooms for patients. The seven cubicles are of different sizes and have bed capacity of four (4), six (6) and eight (8) respectively with limited washrooms which cannot meet the demand of the high number of patients on admission let alone the needs of caregivers some

of whom share the same facilities with the patients. The male ward on the other hand is a one big dormitory with two side wards to cater for the special cases like tuberculosis patients and patients who need to be isolated. It is a 23-bed capacity ward.

The medical department is made up of two specialists, seven medical officers (MO), five house officers, 22 nurses and eight orderlies. These people are responsible for the medical needs of both out and in-patients. The male ward has 9 nurses while the female has 11 nurses. Currently, there are three medical officers who come on ward rounds in the two wards but are not permanently stationed there. Due to inadequate staff, the MOs also attend to out-patients at the main OPD after their ward rounds.

The hospital admits patients with varying health conditions; however, fifteen of them are of great concern. In 2014, HIV/AIDS top the list with 314 cases followed by diabetic mellitus with 307 and hypertension with 262 cases. The following form the top three cases in 2015: hypertension 350 cases, HIV/AIDS recorded 307 and diabetic mellitus recorded 216 cases. Hypertension tops the 2016 admission list with 352 cases, followed by diabetic mellitus with 283 and HIV/AID with 251 cases. These statistics show that whereas HIV/AIDS cases saw a decrease over the past three years, hypertension maintained the first position over the last two years. Other health conditions include cardiac failure, pneumonia, stroke, hepatoma, anaemia, malaria, gastroenteritis, sickle cell disease, chronic kidney disease, urinary tract infections, gastritis and cellulitis. In 2016, the medical ward alone admitted two thousand, six hundred and fifty-three (2653) patients. Out of this number, 2,067 were discharged, 413 died and 38 were referred to other higher level public health facilities. The hospital turned 90 years in 2016 and was celebrated under the theme: *“Celebrating 90 years of excellence in healthcare delivery – achievements, challenges and prospects”*

(Source: Hospital's 2016 Dairy and 2016 Annual Report)

### **3.2. Entering the field**

Each visit of my seventeen (17) month-stay in the hospital was welcomed with smiles by most nurses especially the Ward Matrons (WM). Even though the nurses were aware of my presence and purpose in the hospital, the long stay made them wonder what I was really looking for. One of the Ward Matrons normally asked “Auntie Gladys, are you still around? Are you getting what you are looking for?” Another one with a smile will add “You are here again, I thought you have finished”. Anytime such questions were asked, I explained and made them understand that the study is qualitative and combines interviews with observation and as a result, if data are not handled with care, some vital information needed to understand the topic will be overlooked. I therefore transcribe the recorded interviews after each section to see the trends and themes emerging from the data for further probing in subsequent visits. The nurses’ inability to understand my long stay is due to the fact that most of the studies carried out in the hospital use the survey and after a few days, the researchers are not seen in the hospital. Even though I was given entry by the hospital Administrator in January, 2016, when I went to gather data on the background of the hospital itself in April, 2017, I was requested by the head of research unit to submit my research protocol including ethical clearance from my University since the information I needed is vital. As Mulemi (2010:26), reports “social scientists who have conducted hospital studies have experienced different degrees of difficulty in entering clinical setting.” Sometimes, my presence seems to be a bother to some of the nurses who feel I might be writing something negative about them.

### 3.3. Research design

The study was carried out using the qualitative exploratory case study design because the study was interested in a naturally occurring phenomenon which is lay caregiving. It is also interested in understanding the socio-cultural and institutional factors influencing such a decision and how these lay caregivers negotiate their roles with the health professional within a highly-professional work environment. The choice is also informed by the philosophical underpinnings of constructivist paradigm that truth, for that matter reality, is relative, and it is based on the individual's perspective. Thus, using case study will allow participants to express their views on reality. The qualitative approach is chosen over the quantitative because to Hennink, Hutter, and Bailey (2010) "the main distinctive feature of qualitative research is that the approach allows the researcher to identify issues from the perspective of your study participants and understand the meanings and interpretations they give to behaviour, events or objects". According to Thomas (2012:3) "case study is a kind of research that concentrates on one thing, looking at it in detail and not seeking to generalise". This according to Willis and Jost (2007) is one of the principles of interpretivist researchers who do not seek to find universals in their case studies but seek a full, rich understanding of the context they are studying. As Baxter and Jack (2008:544) argue "qualitative case study methodology provides tools for researchers to study complex phenomena within their contexts and when the approach is applied correctly it becomes a valuable method for health science research to develop theory, evaluate programs, and develop interventions". To Yin (2008:18), a case study is "an empirical inquiry about a contemporary phenomenon, set within its real-world context especially when the boundaries between the phenomenon and context are not clearly evident". Using the qualitative case study approach also means that a smaller number of participants will be used which will enable the researcher to have intense

interaction with the participants in order to get detailed information on the topic under study. Considering the nature and intent of the study, the study is exploratory because according to Hennink et al. (2010) and Thomas (2012) this approach is appropriate when the researcher wants to know more about a phenomenon (what is happening and why).

Yin (2003) identifies four conditions under which a case study design should be considered. These are (i) when the focus of the study is to answer “how” and “why” questions; (ii) when the boundaries are not clear between the phenomenon and context, (iii) when the researcher cannot manipulate the behaviour of those involved in the study; and (iv) when the researcher wants to cover contextual conditions which are believed to be relevant to the phenomenon under study. Thomas (2012) also adds that it is useful when investigating cases that deviate from the norm (outliers). Thus lay caregiving within the professional environment is considered a deviation rather than the norm. This phenomenon however, cannot be understood without the context in which it occurs. Further, Baxter & Jack (2008:545) indicate that case study “ensures that the issue is not explored through one lens, but rather a variety of lenses which allows for multiple facets of the phenomenon to be revealed and understood. It also enables the researcher to study the intricacy and particularity of social phenomena”. This study therefore focuses on the views of both lay caregivers and professionals to understand the phenomenon under study. Since this study is to understand the conditions leading to lay caregivers’ involvement in a professional care delivery system and how the professionals and the lay caregivers negotiate their roles and to generate deeper knowledge and understanding of the phenomenon in order to inform policy, case study is considered most appropriate. The “case” in this study is the negotiation processes and factors that lead to lay involvement and this cannot be understood without the context (hospital environment) in which it occurs (Baxter & Jack, 2008; Miles and Huberman, 1994).



Different authors have identified and categorised case study differently. Yin (2003) categorises case studies as exploratory, explanatory or descriptive and also differentiates between single, holistic case studies and multiple-case studies. Stake (1995) on the other hand identifies case studies as collective, intrinsic and instrumental. Explanatory case study is used if the researcher is seeking to answer a question that seeks to explain the presumed causal links in real-life interventions that are too complex for the survey or experimental strategies while the exploratory is used to explore those situations in which the intervention being evaluated has no clear, single set of outcomes. The descriptive on the other hand is used to describe an intervention or phenomenon and the real-life context in which it occurs. Stake (1995) indicates that intrinsic case study is used when one is interested in a unique situation and the intent of the study is to better understand the case and not with the purpose to generate theory and the results have limited transferability. Instrumental is used to accomplish something other than understanding a particular situation as it provides insight into an issue or helps to refine a theory. Collective case study enables the researcher to explore differences within and between cases with the goal of replicating findings across cases.

Borrowing from Yin (2003) and Stake (1995), this study may be described as “Exploratory-Intrinsic” in that it seeks to explore factors leading to lay caregivers in professional health delivery system and for a better understanding of the topic and how these two caregivers negotiate their roles in a situation where they have unequal power. It is also a single holistic case because it focuses on the negotiation process of the caregivers within the male and female medical wards of the hospital.

### **3.4. The Choice of the Medical Ward**

Even though KCH has many wards and departments, the adult medical ward was chosen for this study. This is because the patients there are adults who can communicate and understand the issue under study to be able to provide the information needed. Also, these patients have serious health conditions which need the attention of the professional caregiver. The patients are also likely to spend more than three days in the ward which is a requirement that gave both patients and their caregivers much lived-experiences of interest to the researcher. To understand the issue of lay caregiving in a professional milieu, it is prudent to choose the adult medical ward. The choice is also informed by time and financial constraints on the part of the researcher.

### **3.5. Target population**

The population of this study comprises people who are not part of the organisational structure of KCH but spend three or more days at the hospital rendering some services to the in-patient. These include relatives and non-relatives who are 13 years and above; patients on admission who can talk; and the professional staff (nurses and doctors) of the hospital who have at least two years working experience in care giving. This population was chosen because participants can articulate their lived-experiences.

Patients who cannot communicate, children under 13 years and visitors who do not take part in the provision of care for the in-patients were excluded from the study.

### **3.6. Data sources**

Data were collected from both primary and secondary sources. To Baxter and Jack (2008), within case study research, the investigators can collect from multiple sources which facilitate

reaching a holistic understanding of the phenomenon being studied. As a result, the researcher did not only collect data from primary and secondary sources but employed multiple data collection approaches such as observation, individual in-depth interviews, key informant interviews and focus group discussions.

### **3.7. Recruitment of Participants**

Before entering the field, a letter was formally written to the administrator of the hospital seeking permission to use the two adult medical wards (male/female) for the study. The administrator in her response informed the Deputy Director of Nursing Services (DDNS) in charge of the said wards to inform the ward matrons. The researcher also sent personal letters to the ward matrons (WM) and permission was sought from them. In the wards, the researcher explained the purpose and intent of the study to the ward matrons who in turn introduced the researcher to the nurses. Through records, the nurses identified the patients who met the selection criteria (those who had spent three days or more at the hospital). The nurses did not introduce the researcher to the patients neither did they participate in the selection of the participants. The patients and health professionals who accepted to take part in the study were asked to sign a written consent form after the purpose and the ethical considerations of the study were explained to them. Due to the nature of the professional's work and the condition of the patients, individual in-depth interviews were conducted lasting between 10 – 30 minutes using the semi-structured interview guide.

For lay caregivers, the researcher employed two approaches to recruit the participants. The first one was to pair patients with their lay caregivers to identify some consistencies in the type of care given and the benefits patients derived from the presence of their caregivers. With this, after the patient granted audience to the researcher, he/she directed the researcher to his/her caregiver

and if the caregiver accepted to take part in the study, a written consent form was given him/her to sign. Those who could not sign had witnesses to sign on their behalf. However, this approach faced some challenges as some of the caregivers were not ready to take part in the study and others were difficult to reach. This approach yielded only few results due to two main reasons. The first one is that, some caregivers of the patients interviewed were not around to be interviewed and even arrangements made with them proved futile while some who were around were not interested in the study. The second major reason is that some patients could not communicate and as a result, pairing them with their caregivers was problematic. Due to these difficulties, the researcher adopted a second approach (snowball) for recruiting participants and this approach yielded better results. With the use of the snowball technique, one caregiver directed the researcher to another caregiver and so on. The challenge with this group of participants is that the stress of thinking about a sick relation coupled with financial difficulties and the fear of the unknown made them uncomfortable to spend much time with the researcher. As a result, individual interviews were conducted between 10 and 30 minutes.

The snowball technique was also used to recruit participants for the focus groups discussions made up of between 6 to 8 members and the interview guide was used for the data collection. Two focus group discussions sessions were conducted. In all these cases, permission was sought from the participants and the interviews were recorded and transcribed or translated later on.

### **3.8. Number of Participants**

To Thomas (2012), a sample size is not what is wanted in a case study. A sample should only show the quality of the whole. Thomas, (2012) suggests that stratifying which means making sure the most important parts of the whole are gotten should make up for the shortfall of limited

sample size. He further indicates that the quality of the study should come about through the clarity of writing, the problems or questions being addressed and methods used, among others. Leininger (2008:19) also adds that “one does not have to always measure everything or all phenomena to know or understand them.” The researcher, therefore, employed the principle of saturation to determine the sample size. Data reaches saturation when no new information is given by the participants on the topic under study. In this study, saturation was reached with the 27<sup>th</sup> lay caregiver. Interviews conducted after the 27<sup>th</sup> participant showed no new data and as a result, the researcher ended the study with the 32<sup>nd</sup> lay caregiver. Saturation for patients was reached with the 12<sup>th</sup> participant.

Since the hospital is not a permanent residence for patients and their caregivers, the researcher used purposive and snowball combined with stratified purposeful sampling because the population under study is heterogeneous. Heterogeneity of the population is seen in sex and social status within the hospital. Purposive and snowball sampling techniques were used because these are non-probability sampling techniques which are helpful in collecting data on a floating population and also on people not easy to reach. These techniques enabled the researcher to select samples from which the most could be learnt about the research questions. The snowball sampling helped in getting the participants because those who stayed with the sick at the hospital knew each other and the application of this technique actually helped in getting the participants concerned.

Stratified purposeful sampling focuses on characteristics of particular subgroups of interest and also facilitates comparisons among the subgroups. This strategy is similar to stratified random sampling (samples are taken within samples), except that the sample size is typically much smaller than stratified random technique applied in quantitative research method. However, the

main goal of this strategy is to capture major variations (Patton, 2001). Since the population under study is heterogeneous (lay caregivers, patients themselves, and professional staff), the stratified purposeful sampling was considered appropriate so that samples would be obtained out of every stratum of the population.

Using the stratified purposeful samplings, the researcher divided the participants into non-overlapping strata of lay caregivers, patients, doctors and nurses just as it is done in stratified random sampling. However, instead of selecting participants randomly as done in the stratified random sampling, the researcher selected participants purposively.

Fifty-two (52) interviews were conducted, transcribed and coded. This is made up of thirty-two (32) lay caregivers, twelve (12) patients, six (6) nurses and two (2) doctors. Even though the researcher went to the field having in mind that medical officers and nurses (as health professionals) would provide rich data on the subject, it was realised that nurses should be the best people to provide key information on care for the patients in the wards. This is due to the fact that the nurses spend much time in the ward with patients and play greater roles in the routine care and day to day management of the patients than doctors. Doctors only come on ward visits or rounds to check on how the patients are responding to treatment and to prescribe medicines for those who have not recovered or discharge patients who have sufficiently responded to treatment. Two focus group sessions made up of six (6) and eight (8) discussants respectively were conducted with some caregivers to complement data collected from the individual in-depth interviews.

### **3.9. Pilot study**

There was the need for a pilot study to be carried out to test the appropriateness of the tools and the strategies for the data collection. The Korle Bu Teaching Hospital was used for this purpose. The pilot study helped the researcher to develop the techniques of taking observational notes and how to conduct individual in-depth interviews. It also helped in reframing of some questions. Through this study, additional questions (3) were added to the questions that the researcher went to the field with. The pilot study also helped to ensure trustworthiness of the data through testing of the instruments for the data collection.

The pilot study was not without challenges. Both the health professionals and lay caregivers initially showed signs of fear, mistaking the researcher for a journalist. This fear was entertained because a famous undercover journalist had published extensively malfeasance in some public institutions in the country. However, with the production of her student's identity card and the permission letter, the fear was allayed. The researcher also explained the nature and intent of the study to the participants and assured them of confidentiality and anonymity. This helped the participants to have confidence in the researcher.

### **3.10. Data Collection Approaches/Instrument**

Since the hallmark of a good qualitative case study is to present an in-depth understanding of a case, multiple data collection methods were employed (Creswell, 2013; Thomas, 2012; Yin, 2013). These include interviews, observations and focus group discussions. The semi-structured interview guide and digital audio recorder were used to collect data from all the participants. This is because semi-structured interviews are conducted with a fairly open framework which allow for focused, conversational two-way communication. Semi-structured interviews also

allow individuals to disclose thoughts and feelings which are clearly private. Since semi-structured interviews often contain open-ended questions and discussions may digress from the interview guide, it is generally best to tape-record interviews and later transcribe these tapes for analysis. The researcher, therefore, applied these principles during the face-to-face interview with the participants. In-depth interviews were conducted with participants and key informants. The questions on the interview guides were carefully set in order to get the most important information geared at answering the objectives in the shortest possible time. This is because of the pressure of work on the part of the health professionals and emotional instability on the part of some caregivers due to the fear of the unknown. However, further probes were given to get to the depth of the information needed.

The technique of observation as a data collection tool was also employed to collect data to complement those collected using interviews. This is due to the fact that observation helps in getting information which may be insignificant to the interviewee but may be of importance to the researcher. To Creswell (2008), unusual aspects of the study can be noticed during observation and also provide first-hand information to the researcher. In this study, the researcher applied participant observation using the observation protocol. In the ward, the complete observer approach, a kind of non-participant observation was employed where the researcher only observed the activities of both lay caregivers and nurses as they carried out their respective duties. Since the research participants are aware of the purpose of the researcher's presence in the ward, observations were done concurrently with the interviews. This is because doing observation on separate days may interfere negatively on the data to be collected as both HPs and LCs will pretend to be doing things to save face and data might not reflect the true situation on the ground. The researcher succeeded in her observational role due to the rapport she



developed with the nurses and her presence was always welcomed with smiles. The long stay (17 months) on the field also facilitated observation. The researcher on a number of occasions helped caregivers to raise/lift their patients from the bed and assist them with some care.

At the visitors' hostel where some caregivers stay until their patients are discharged, the researcher employed complete observer role in studying some of the activities of the lay caregivers and the relationship that developed among them. On the first visit to the hostel, the researcher explained the purpose of the study to the caretaker and the caregivers around. However, by becoming a friend to a physically challenged woman who was taking care of her only son and who had spent more than a month at the hostel (as at the time this study was conducted), the researcher easily got access to the hostel residents. On subsequent visits, this caregiver, the physically challenged woman, introduced the researcher to other caregivers in the hostel as a researcher and a student.

The observation at both the ward and the hostel was made possible by one of Leininger's (1991a) research enablers, the "stranger to trusted friend enabler". This enabler is an aspect of ethnonursing research method in which the researcher at first a stranger, moves into the status of a trusted friend as a result of frequent interactions with research participants. According to Leininger (2008), this enabler is a powerful means for assessment, self-disclosure and self-reflection which guides the researcher while on the field from the beginning to the end of the study. Data from this enabler is believed to provide high reliability and confirmability as the researcher moves from a stranger role to becoming a trusted research friend. It is further believed that this enabler makes it possible for the researcher to enter the world of the key and general participants to learn about care meanings and practices as emic data can be authentically and consistently obtained.

Two focus group discussions were conducted to supplement data collected using the individual in-depth interviews. This approach also yielded good results as members were more open to talk about the ills and the challenges they went through to the surprise of the researcher. The open nature in which the discussants talked about the negative things happening in the hospital may be due to the fact that the group provided the discussants anonymity.

### **3.11. Reliability and Validity**

There are two important issues in measuring the quality of every research project. These are validity and reliability. Reliability, according to Neuman (2007), means dependability or consistency. It suggests that the same thing is repeated or recurs under identical or very similar conditions. Validity on the other hand means truthfulness. It refers to the bridge between a construct and the data. It further means that the instrument is measuring exactly what it is meant to measure. However, Neuman (2007)) added that qualitative researchers are more interested in authenticity than validity. Authenticity means giving a fair, honest and balanced account of social life from the viewpoint of someone who lives it every day. In a similar vein, Wahyuni (2012) reports that, some social scientists (Kalof, Dan and Dietz 2008; Bryman 2012) explain that reliability and validity per se cannot be practically used as criteria to assess qualitative research. Rather some alternative terms have been used to sensitise reliability and validity of qualitative research. There are four criteria of research trustworthiness developed by Lincoln and Guba (1985) to evaluate the quality of qualitative research. These are *credibility* which parallels internal validity, *transferability* which resembles external validity, *dependability* which parallels reliability and *confirmability* which resembles objectivity. According to Nahid (2003)), although reliability and validity are treated separately in quantitative studies, these terms are not viewed

separately in qualitative research. Instead, terminology that encompasses both, such as credibility, transferability, and trustworthiness is used. Creswell (2008) citing Gibbs (2007) indicates that, qualitative reliability indicates that the researchers' approach is consistent across different researchers and different projects. Different approaches have been suggested by different authors as to how reliability and validity can be ensured in a qualitative study.

From Yin's (2003) point of views, to ensure reliability of qualitative data, researchers need to document the procedures of their case studies and to document as many of the steps of the procedure as possible. Yin (2003) shares similar view with Lincoln and Guba (1985) who have identified "inquiry audit" as a means of ensuring reliability in qualitative research. Inquiry audit according to Lincoln & Guba (1985) is demonstrated by a carefully documented research process. In addition to what these authors suggest, the researcher employed two of Gibbs' (2007) four reliability procedures as follows: check transcripts to make sure that they do not contain obvious mistakes made during transcription and make sure that there is not a drift in the definition of codes and a shift in the meaning of the codes during the process of coding. This was accomplished by constantly comparing data with the codes and by writing memos about the codes and their definitions.

To Baxter and Jack (2008), a researcher using case study can ensure validity or credibility by providing enough details of the work to the readers. In order to achieve this, the researcher has to provide the participants voice in the presentation of data. Further, the research questions were clearly written and administered; purposeful sampling strategy was employed in recruiting participants; data was collected and managed systematically and were analysed correctly using Nvivo Pro 11. The researcher also used the principle of triangulation of data sources, sampling and researcher as the primary instrument for data collection to ensure credibility or the truth

value of the study. The researcher also visited the hospital frequently at least three times in a week and spent more than a year at the study site in order to have intense exposure to the phenomenon under study. Field notes were copiously written and three other people were involved in the transcription/translation of some data collected. These transcribers were tutored by the principal researcher on how to transcribe data. This was done to make sure that the data gathered were valid.

### **3.12. Data Handling**

Data analysis in qualitative research is not a one stop activity as in quantitative research. It is an ongoing process and starts immediately the researcher starts collecting data. Therefore, after every field work, the researcher transcribed the recorded information, coded the data by classifying or categorising individual pieces of data coupled with some kind of retrieval method. Coding helps in identifying the various emerging themes. Writing of analytic memo is also important in analysis of qualitative data because memos serve as reminders about what is meant by the terms used and provide building blocks for a certain amount of reflection and also helps in keeping in mind the language of the people in their social contexts. As a result, the researcher employed this technique. The researcher also did concept mapping which helped in the establishment of relationships between variables. The Nvivo 11 Pro software was used to process the data electronically.

### **3.13. Ethical considerations**

This study received approval from the Ethics Committee for the Humanities (ECH 020/15-16) of the University of Ghana. Permission was also sought from the administrator of the hospital. Even though it is the desire of every researcher to get as much data as possible to be able to write a

comprehensive and authentic research paper, the right of the informant must be taken into consideration. For this reason, the following ethical rules were observed during data collection: informed consent, the right to withdrawal at any time, anonymity, confidentiality and causing no physical or emotional harm.

Informed consent was achieved by providing adequate information on the intent and purpose of the study before the participants signed the consent form. Each participant in individual interviews signed separate consent form. Education on the right to withdraw at any time was given to the participants prior to participation and was also stated in the written consent form. As a result, a caregiver decided to withdraw along the way as she felt the researcher was taking too much of her time (only five minutes into the interview) and was no longer comfortable with the recording of her voice. By doing no harm, the researcher made sure that no information given by the participants is misused to exploit their vulnerability (Simons, 2009). As much as possible, trust and respect was built with participants through building of good relationships with them.

Another ethical issue the researcher considered is giving voice and participant control. This was achieved by allowing participants to edit their own comments through playing back of the recorded audio. Confidentiality was ensured by assuring the participants that no personal information given would be made public and only what the participant wanted to make public would be relayed. This assurance given made the participant speak openly and honestly.

### **3.14. Limitation**

Generalisation of the findings is the main limitation of the study. This is due to the small number of participants used and the choice of a single hospital. As Zucker (2009) indicated,

generalisation of case study findings is limited to the case itself or types of cases. While accepting the limitation as a result of the small sample size, it must be noted that the findings help in throwing more light on the issue under study.

### **3.15. Field challenges**

Even though some challenges have been mentioned in the introduction of this chapter, the following challenges have to be put on record. The greatest challenge encountered is the inability of all participants (lay caregivers, health professionals and patients) to spend much time with the researcher. This was due to situational factors. The lay caregiver is under stress for caring coupled with financial difficulties and the uncertainties of the unknown. The patient due to his or her condition, is not ready to talk beyond certain limit while due to the pressure of work, the health professional will give excuses and sometimes end interviews half-way. In order to get the data needed to address the objectives, questions were directed to the objectives. The researcher also followed some of the participants to their homes for the interviews.

The second challenge is the unwillingness of prospective participants to participate in the study. While some thought the study has no financial benefits to them, others also felt they have been exploited by researchers for personal gains in the past and their views have also not been articulated. To address the former concern, the researcher made the participants understand that even though they may not derive immediate benefit from the study, the findings would help the researcher to get a better understanding of the phenomenon and findings may influence policy on care in institutional settings which will benefit future patients and lay caregivers. The researcher further explained that it is the inability of policy makers to implement research findings that has

resulted in a large number of social problems. Participants were therefore compensated with a large bottle of water after they have completed the interview.

In conclusion, this chapter discusses how data were gathered for the study. It focuses on the various techniques employed and the challenges encountered during the field work. The strategies adopted to minimise some of the challenges were also outlined. The next chapter gives a brief background into Ghana's health policies over the years

## **CHAPTER FOUR**

### **SOME HEALTH SERVICES/POLICIES IN GHANA**

#### **4.0. Introduction**

In all countries, citizens' access to quality health facilities and their enjoyment of good health is crucial; as it is often said a healthy mind is found in a healthy body. Since good health is also linked with higher productivity, health issues in Ghana have been given much attention over the years. The United Nations (UN) also considers access to health facilities and enjoyment of good health by all as a fundamental human right. Thus post-colonial administrations have put some measures in place to provide better health for Ghanaians. However, the provision of quality professional health care was a challenge especially in the early 1980s when as a result of serious national financial crisis, the health system collapsed: hospitals had no equipment, food, beddings and other logistics. As logistics were in short supply, relatives had to come in to save relations on admission. Even though Ghana's economy had improved over the years, family members' involvement in care for relations on admissions has not ceased but rather increased. This chapter, therefore, discusses some of the policies made by Governments over the years to provide quality health care for the citizens.

#### **4.1. Colonial and Post-Colonial Policies**

According to Addae (1997), medical policy in the then Gold Coast became not only necessary but urgent due to two main reasons. One was an increased in the number of the Europeans population of British officials, missionaries and businessmen in the colony. He indicated that "the rise in European population was caused by the rapidly expanding British colonial administration and the significant increase in British business (commercial and mining) and



missionary activities. The presence of these Europeans in the Gold Coast therefore created concern for the European well-being”(Addae, 1997:29). The second reason was that there was high mortality rate among the Europeans as the mortality rate increased from 31.2% in 1893 to 66.9% in 1895 and this high death rate was caused mainly by malaria. Even though the reasons were initially meant to promote good health among the Europeans, they benefitted the locals as well (Anyinam, 1989).

In the quest to promote good health among the Europeans, the army medical services unit at Keta, Accra, Cape Coast and Elmina were turned into civil health facilities in 1878 and the first civil hospital with admission facility was built in Accra. However, the initial health policy was to protect the well-being of the European. As a result, health facilities were concentrated at where the Europeans could be found and the towns with the indigenous people were left without medical facilities (Addae, 1997; Anyinam, 1989). Health personnel with European origin were brought to attend to the health needs of the people and European officials and non-officials, African government officials, troops, police and the Hausa constabulary were the people who benefited mostly from these health care services (Addae, 1997; Arhinful, 2003)

The policy to extend medical services to the majority of indigenous people was moved by Governor Clifford when he arrived in the Gold Coast in 1912. He therefore decided to embark on the extension of health care services to the remote areas of the country and also to educate the indigenes to appreciate the benefits they could derive from accessing the modern medical care services. Clifford also embarked on the establishment of dispensaries manned by reliable dispensers among the indigenous people even though he could not achieve much in this regard due to the limited number of qualified medical staff as the few that were there were concentrated

in the urban centres of the country. Despite this challenge, Clifford trained the paramedics of the Medical Department of the Gold Coast to run the dispensaries.

Addae (1997) further reports that after Clifford, came governor Guggisberg who laid the foundation for all health policies in Ghana and identified Guggisberg's public health policy to have been grouped under the following headings namely: (a) the care of the sick (b) professional training of African medical and public health officers (c) infant welfare (d) general health education of the people (e) sanitation and improvement of towns and villages (f) medical research (g) and epidemics.

The 1950 medical policy of the Gold Coast which was based on the recommendation of the Maude Commission of inquiry into the health needs of the Gold Coast has the expansion of Medical Field Units as one of its top priorities. Improvement of existing hospital facilities and a moratorium on the building of new ones, establishment of health centres throughout the country, and an increase in the number of dressing stations constituted the rest of government's medical policy.

When Dr. Kwame Nkrumah took over the administration of the colony in the mid-1950s, he also put some measures in place to improve the health condition of the people. Alatinga and Williams (2014), report that the plan for better health of the people was made known in the first president's speech. He is quoted to have said "My first objective is to abolish from Ghana poverty, ignorance and disease. We shall measure our progress by the improvement in the health of our people. The welfare of our people is our chief pride, and it is by this that my government will ask to be judged" (Alatinga and Williams, 2014: 363). Under the Convention People's Party government therefore, a number of new hospitals, clinics and health centres were built while

some existing ones were expanded. Some polyclinics such as the Korle Bu Polyclinic were built mainly to attend to out-patient needs in order to ease the congestion on the regional hospitals. The government also abolished private practice in government health facilities especially hospitals and as a result, medical services became free to both Ghanaians and non-Ghanaians. Literature revealed that doctor-patient ratio was also increased as the Nkrumah government granted scholarships to Ghanaians to study medicine abroad and return to help in health delivery. By 1962, six nursing training schools were built to train local nurses and midwives. Health inspectorate units were also set up at the district levels to enforce by-laws on sanitation and environmental cleanliness.

Subsequent governments after Nkrumah also put policies in place to improve health care services. However, health promotion within the public sector gained currency after the WHO's first international conference on health promotion was held in Ottawa, Canada in 1986 where a charter for action was developed to achieve "Health For All" by the year, 2000. The charter suggested five strands for health promotion actions and this include building a public health policy, creating a supportive environment, strengthening community action, developing personal skills and re-orienting health service. Health education was recognised by the health sector in Ghana to promote the Primary Health Care (PHC) concept in order to achieve health for all by the year 2000. Before the introduction of the PHC concept in the late 1980s, Ghana's health sector had gone through some policy reforms and this started as far back as the colonial period.

Primary health care is defined as the "essential health care made universally accessible to individuals and families in the community by means acceptable to them through their full participation and at a cost that the community and the country can afford" (WHO 1978). This concept was developed by WHO when the organization realised the widening gap between the

poor countries which could not afford to pay for healthcare services and the rich countries which could afford to do so. This concept, according to the National Health Learning Manual Commission (NHLMC 2002), became attractive to Ghana and most developing countries due to the following circumstances among others: the cost of providing health care delivery had become expensive, health services were no longer free to the individual consumer and there were no viable health insurance schemes. Ghana therefore developed a strategy to implement the PHC concept and the “aim of that strategy was to reduce high mortality and morbidity rates due to the conditions for which easy treatment and control existed” (NHLMC 2002).

In the year 2000, a close-to-client service delivery was adopted in Ghana through Community Health Planning and Services (CHPS) where community health nurses are placed in communities to offer public health, outreach and limited clinical service and serve as the first point of contact and referral. Each CHPS compound is supposed to serve on average a population of 500 and are scattered in the rural areas of Ghana. This intervention also has its fair share of the problems confronting Ghana. Lack of logistics, personnel, structures/building to house the few working tools and personnel, access to utility such as water and electricity are but some of the few of the numerous problems reported in the media frequently. However, the CHPS compound is in operation.

#### **4.2. Financing Health Care in Ghana**

Before Ghanaians started paying for health care services in public hospitals in the early 1970s even though the fees were low, health services were provided free of charge to the people throughout the country. Due to the free nature of health care, some people began abusing the use of the health care system and as a result, fees were introduced in the early 70s to discourage the

misuse of health services. However, as Ghana's economic condition worsened in the 1980s, full fee paying for health care services became the order of the day as a result of the directive from the International Monetary Fund (IMF) and the World Bank to revamp Ghana's deteriorating economy.

Badasu (2009) and Alatinga and Williams (2014) indicated that in 1992, full user-fees payment was introduced in all public health centres for all categories of persons (even though children below age five (5) and adults above 70 years were exempted from paying for certain services like consultation fees). Under the full user-fees payment, unless one paid, one would not be given medical attention. Thus "Cash and Carry" was one of the World Bank and IMF's recommendations for Ghana to revamp the country's economy which suffered crisis from the mid-1970s to early 1990s. This system continued until around the late 1990s when a mutual health scheme was started on a pilot basis in some deprived selected districts of Ghana. However, in early 2000, the government decided to roll out the health insurance scheme first on district basis. Today we have the National Health Insurance Scheme (NHIS) running.

The National Health Insurance Scheme (NHIS) is a social intervention programme introduced by the Government of Ghana to provide financial access to quality health care for residents in Ghana. This scheme was established under Act 650 of 2003 to provide basic healthcare services through mutual and private health insurance schemes. The scheme is currently funded by the National Health Insurance Levy (NHIL), which is 2.5 % levy on goods and services collected under the Value Added Tax (VAT); Social Security and National Insurance Trust (SSNIT) contributions per month; premium paid by the informal sector subscribers; and returns on the National Health Insurance Fund (NHIF). The NHIS according to the NHIS Subscriber Handbook (2015), covers over 95% of all ailments that are reported in Ghanaian health care facilities and it

covers services such as Out-Patient Department (OPD) Services, oral health services, maternity care, emergencies, and In-Patient Department (IPD) Services. In 2008, Free Maternal Care (FMC) was added as well as HIV/AIDS symptomatic treatment for opportunistic infection in 2012, Act 852, 2012, (Alatinga & Williams, 2014).

The scheme however excludes the following services among others: rehabilitation other than physiotherapy, HIV antiretroviral medicines, dialysis for chronic kidney failure, cancer treatment other than cervical and breast and medical examination for purposes of employment, school admissions, visa application, driving license etc. To continue benefiting from the NHIS, subscribers must renew their membership with the scheme through the payment of a premium (as determined by the fund manager) on annual basis and failure to renew membership on time (three months after expiration of time) is also tantamount to sanctions. For example, members who fail to renew their membership three months beyond the date of expiration shall have their membership deactivated from the NHIA membership database until they renew it. Defaulting members who renew their membership after three months of expiry will be required to observe a three-month waiting period before accessing health care under the NHIS (NHIS Subscriber Handbook 2015:15). Currently, the premium paid as subscriber is as follows: twenty-seven Ghana cedis (Gh¢27) for new registration as non-SSNIT contributor or informal sector employee between eighteen and sixty-nine years (18-69), SSNIT contributors pay 2.5% of their SSNIT contributions as insurance premiums directly to the scheme NHIA in addition to a cash of five (Gh¢5) as registration fees. The Scheme however, exempts children under 18 years of age, persons with mental disorders, pregnant women, the indigent (very poor), SSNIT pensioners (60years and above), and the aged-70 years and above from paying an annual premium. These categories of beneficiaries however, pay registration fees as determined by NHIA and currently,

they pay five Ghana cedis. The scheme is however confronted with so many problems including finance, abuse or misuse of the services by both the subscribers and some service providers and political interference among others. In order to curb some of these problems such as abuse of the scheme by subscribers and bloating of claims by some service providers, capitation, which is one of the provider payment mechanisms for running health insurance was piloted in the Ashanti region and it is now being introduced in all parts of the country. The other two provider payment mechanisms are fee for service provider and diagnosis related groupings.

The introduction of capitation which is a provider payment mechanism in which providers in the payment system are paid, typically in advance, a pre-determined fixed rate to provide a defined set of services for each individual enrolled with the provider for a fixed period of time is to aid improve access to care services. The amount paid to the provider is irrespective of whether that person would seek care or not during the designated period” In a fee for service provider payment method, the provider typically lists the different services that they have provided for the client and the cost of each service and requests payment whereas in the diagnosis related groupings payment method, related diagnoses are grouped together and the average cost of treatment in that group determined. Providers are therefore paid according to the diagnosis they give their client ([www.nhis.gov.gh/capitation.aspx](http://www.nhis.gov.gh/capitation.aspx)). Even though the scheme aims at providing financial access to quality health care, the story is quite different as told by the caregivers and in-patients at the study site.

The above are but some of a few acts Ghana has passed towards achieving quality health for her citizenry. These are health institution and facilities Acts (HIFA) 829, public health act 851, mental health act 846, specialist health training and plant medicine research act, 833. As said earlier, the space in this thesis is too small to discuss the various health polices made in Ghana.

However, mention must be made of the malaria control, maternal health and under-five year programmes which are given prominence in the country.

Irrespective of the above national policies aimed at providing quality and accessible health care to the citizens, there are no clear policies on lay caregivers' involvement in health care. However, the rights of patients and their family members are given recognition in the Patients' Charter of Ghana. Below is the excerpt from the Patients' Charter.

#### **4.1. Excerpt from the Patient's Charter of Ghana**

The charter addresses:

- (a) The right of the individual to an easily accessible, equitable and comprehensive health care of the highest quality within the resources of the country.
- (b) Respect for the patient as an individual with a right of choice in the decision of his/her health care plans.
- (c) The right to protection from discrimination based on culture, ethnicity, language, religion, gender, age and type of illness or disability.
- (d) The responsibility of the patient/ client for personal and communal health through preventive, promotion and simple curative strategies.

#### **The Patient's Right**

- (a) The patient has a right to quality, basic health care irrespective of his/ her geographical location.
- (b) The patient is entitled to full information on his/ her condition and management and the possible involved except in emergency situations when the patient is unable to make a decision and the needs for treatment is urgent.



- (c) The patient is entitled to know of alternative treatment(s) and other health care providers within the service if these may contribute to improve outcomes.
- (d) The patient has the right to know the identity of his /her caregivers and other persons who may handle him/her including students, trainees and ancillary works.
- (e) The patient has the right to consent or decline to participate in a proposed research study involving him or her after a full explanation has been given.
- (f) A patient who declines to participate in or withdraws from a research project is entitled to the most effective care available.
- (g) The patient has the right to privacy during consultation, examination and treatment. In cases where it is necessary to use the patient or his/her case notes for teaching and conferences, the consent of the patient must be sought.
- (h) The patient is entitled to confidentiality of information obtained about him/her and such information shall not be disclosed to a third party without his/ her consent or the person entitled to act on his /her behalf except where such information is required by law or in the public interest.
- (i) The patient is entitled to all relevant information regarding policies and regulations of the health facilities that he/ she attend.
- (j) Procedures for complaints, disputes and conflict resolution shall be explained to patients or their accredited representatives.
- (k) Hospital charges, mode of payments and all forms of anticipated expenditure shall be explained to the patient prior to treatment.
- (l) Exemption facilities, if any shall be made known to the patient.
- (m) The patient is entitled to personal safety and reasonable security of the property within the confines of the institution.
- (n) The patient has the right to a second medical opinion if he/she so desires.

### The Patient's Responsibilities

The patient should understand that he/she is responsible for his/her own health and should therefore cooperate fully with healthcare providers. The patient is responsible for:

- (a) Providing full and accurate medical history for his/her diagnosis, treatment, counseling and rehabilitation purposes.
- (b) Requesting additional information and or clarification regarding his / her health or treatment which may not have been well understood.
- (c) Complying with prescribed treatment, reporting adverse effects and adhering to follow up requests.
- (d) Informing his/her health care providers of any anticipated problems in following prescribed treatment or advice
- (e) Obtaining all necessary information which has a bearing on his/her management and treatment including all financial implications.
- (f) Acquiring knowledge on preventive, promotive and simple curative practices and where necessary to seeking early professional help.
- (g) Maintaining safe and hygienic environment in order to promote good health.
- (h) Respecting the right of other patients/clients and health service personnel.

NB: These rights and responsibilities shall be exercised by accredited and recognised representatives on behalf of minors and patients who are unable for whatever reasons to make informed decisions by themselves.

In all health care activities, the patient's dignity and interest must be paramount.

(Source: Ghana Health Service)

It must be noted that patients and their caregivers in this study lacked knowledge on the existence of the Patient's Charter. As a result, they are not able to claim their rights. For example, even though the Charter entitled the patient to full information on his/her health condition, this right is often trampled upon by health professionals. Most of the patients and their caregivers in this study lacked knowledge on the health conditions of the sick. Furthermore, access to quality basic health care is a challenge especially to the rural poor. It was discovered on the field that health professionals pay little or no attention to the Patients' Charter. The next chapter focuses on the issue of lay caregivers and health professionals within the hospital settings.

## **CHAPTER FIVE**

### **LAY CAREGIVERS IN THE HOSPITAL CONTEXT**

#### **5.0. Introduction**

One of the objectives of this study is to identify the factors that influence lay caregivers to provide care in the hospital environment. It is therefore important to describe the lived-experiences of these caregivers in their new environment.

The life of lay caregivers in the hospital milieu can best be described as a period of “stress and storm” characterised by heightened emotionality. The desire to get a sick relative well and the anxieties and dilemmas that go with it, put so much stress on caregivers. The caregiver is further stressed, considering the quantum of resources both material and human needed to provide such care. Money, human energy and time among others are never spared when it comes to the provision of care for the sick. The caregiver is not only stressed up but faces a storm from the numerous challenges that confront him or her while providing care for a sick relative in the hospital environment. In an attempt to care for the sick, lay caregivers relegate opportunistic infections to the background. As a result, some end up sick and are sometimes treated alongside those on admissions while others ignore their own health for the benefit of others. This chapter, therefore, discusses lay caregivers within the hospital environment and focuses on how they accommodate themselves, categories of caregivers, conditions of the sick, types of care provided and the challenges that confront them.

#### **5.1. The Residence of the Lay Caregivers**

The hospital has a Visitors’ Hostel built purposely by the Management of the hospital to house lay caregivers. It is a five (5) room unit building. Four of such rooms are single rooms with a

porch. The caretaker of the hostel occupies one of the single rooms. While two of the single rooms are occupied by female caregivers, the remaining one is for the males. The female single rooms are furnished with four single beds each while the one for the males has four (4) double decker beds. The fifth room, a bigger room which may be called a dormitory, also contains six (6) double decker beds and a space to spread additional mattresses. The visitors' hostel can accommodate only 28 caregivers at a time. Women have 20 beds while men have eight. The hostel has wash rooms, kitchen and stores which are used by the caregivers. Items such as cooking utensils, coal pots, a mortar for pounding fufu and palm nut are all made available for the use of the caregivers. Attached to the hostel are two summer huts to shelter the caregivers during the day but some have turned the place into a sleeping place during the day and at night. The cooking utensils and the summer huts were all provided by the hospital authority.

The cost of using the hostel is two Ghana cedis (Gh¢2) a day. Out of this amount, users sleep on foam mattresses, use electricity to charge phones and even turn on the fan, use water for all purposes, visit the washroom; use the coal pot and some available cooking utensils all for free. According to the nurses, the revenue accruing from the two Ghana cedis (Gh¢2) levy is used to pay for public utility services and also to carry out maintenance on the building. The rooms are however too few to meet the needs of the large number of caregivers who patronise the facility. Hence most of them use the Out-Patient Department (OPD) seats and any available space as their beds since it is free sleeping there. One caregiver intimated:

*“Accommodation is my greatest headache because we came with a sick person. However, in the night we do not find any decent place to sleep. We are sacked from the room and nobody thinks about our safety or provides any place for us. When you find a piece of wood, you lay your head on it and pray that day will break quickly. It is one of the major causes of our poor health condition. We need to be in good health in order to take care of*

*the sick but we do not have anywhere to sleep. We sleep on benches and wake up with bodily pains. They should get us accommodation at a price affordable to everybody for us to be healthy so that by the time the sick is discharged, the caregiver will also be in good health. Sometimes, the sick may get well and later you the caregiver also become sick due to the challenges we go through. They have to work on the toilet for us. The place must be kept clean. The toilets are only two while the patients are many. Sometimes, you want to go there while someone is already on it. People come to the hospital with different health conditions and someone goes to spend so much time on it and by the time you realise, another person might have soiled herself. So, it is not good for such a big number to be using only two toilets. The bathrooms are also not sufficient.”*

The above statement captured the accommodation challenges facing lay caregivers at the Koforidua Central Hospital. With the exception of two who lived in the visitors’ hostel, the rest (30) including the thirteen who participated in the two FGDs all found their own accommodation.

As indicated earlier, the visitors’ hostel can accommodate only 28 caregivers at a time. However, the Koforidua Central Hospital is a referral point for almost all the public and private hospitals and clinics in the region and admits over 100 patients from the immediate and remote areas of the region. Shortage of accommodation for relations of patients on admission has compelled LCs to utilise any available space in the hospital as sleeping place in the night. Therefore, the floors in the various wards, the benches in the various OPDs become beds at night. In the desperate search for a place to sleep at night, lay caregivers pay little or no attention to the negative health implications associated with the use of these unapproved sleeping places.

### **5.1.a The Official Attitude**

When lay caregivers were asked whether they were permitted by the hospital authority to sleep on the floor in the ward, some claimed they did so at the blind side of the nurses; some said they

were asked by the nurses to stay by their patients. It was found that while some slept on pieces of cloth spread on the floor, others brought their own mattresses from the house. Anyina indicated:

*“I don't sleep at the hostel but I sleep in the ward. This is my mattress” (pointing at a folded mattress under the mother's hospital bed)*

When asked whether the nurses were aware of the presence of her own mattress in the hospital, she answered in the affirmative even though some said the sleeping was done at the blind side of the nurses. The caregiver intimated:

*“The nurses have seen the mattress but have said nothing about it. When they come to clean this place in the morning, I normally fold it and put it under the bed...I do not sleep here in the day but after 9 pm when they (nurses) have finished with their rounds and gone to sleep. I spread the mattress and sleep. So there is no problem.”*

Anyina's story has two countervailing effects: indicates the nurses have accepted her and the mattress in the ward in order to enable her run emergency errands at night if the need arose. In the same vein, she avoids payment of accommodation fees whether in the official residence of the hospital or in a hostel in town and this saves her some money. However, this should be of great concern to health policy makers because the mattress and the lay caregiver could be potential sources of nosocomial infections: if the mattress is sent back home without proper fumigation, it may have health implication for other members of the family who may use it. However, Anyina has no other option than to put up with this condition. Similar stories were shared by other LCs except that they slept on pieces of cloth spread on the floor and not on a mattress. This is the case of Hajia, a 72- year old mother who spread cloth on the floor by her daughter's bed. In some cases such as that of this 72 year old mother, the health professionals did ask the LCs to stay in the ward due to the conditions of their patients. Such 'preferential' treatments are permitted for non-ambulant, agitated or unconscious patients. This is done so that

the caregivers will keep a constant eye on the patient as some patients attempt to remove the oxygen and infusions set on them. Their presence in the ward aids the health professionals in attending to the patient.

Those who could not use the floor found rest in plastic chairs. A 57-year old kenkey seller and several others were confronted with this challenge. She complained bitterly:

*“We have not had a place to lay our heads, since we came here. We have always been sleeping in the chair and can you imagine the pains in it? That is my problem”.*

The majority of the participants who could not find their way inside the wards used the main OPD benches; benches at other departments and any open place as beds. They were disturbed occasionally by the hospital security men (HS) and constantly by mosquitoes as well. Caregivers complained they are driven away by the security men (HS) when seen at any other place apart from the visitors’ hostel. This practice is however common during the day. However, at night, they are allowed to use only the main adult OPD benches. At the OPD of the children’s department is the inscription **“DO NOT SLEEP HERE, THIS PLACE IS NOT FOR SLEEPING”**. This is typed and pasted on the wall. This inscription is visible and welcomes anyone who goes to the children’s department OPD. This and similar posters are meant to restrict caregivers from using any available space for rest. Despite these attempts, caregivers continue to use any available space for sleep.

In an attempt to drive away mosquitoes, the LCs use the ceiling fan, but met opposition from the hospital security men. Most of the LCs complained the security men prevent them from using the fan. As one of the observed:



*“We sleep at the OPD on benches which give us bodily pains. Even when we turn on the fans to drive away mosquitoes, they (the hospital security men) put them off. They even chained some of the benches so that we cannot sleep on them.”*

When asked why they do not sleep at the hostel provided by the hospital, three reasons came out: limited space, cost and ignorance of the existence of the facility. As said earlier on, the hostel can accommodate a maximum of only twenty-eight people at a time and the number of caregivers far outnumbered beds available. Some study participants complained that the place was already full before they arrived at the hospital. This complaint was made by only a few of the participants. The caretaker of the hostel however indicated that the place is only fully occupied during the heavy rainy seasons. The majority of the caregivers also cited cost or financial difficulties as their inability to patronise the place: the common response that came from discussants when asked why they were not using the hostel was a chorus “Yen ni sika” (we don’t have money). This was the complaint of most of the individual participants as well. However, the cost of using the hostel is only two Ghana cedis (Gh¢2) a day and this amount covers the use of all facilities at the hostel.

However, those not resident in the hostel, pay fifty pesewas when they bathe, thirty pesewas when they visit the toilet and buy water for other purposes, an amount which is equal to paying for the hostel. As a result of this, some LCs use the washrooms and the bathrooms in the wards when they go to attend to their patients. Some of them justified their decision on the grounds of a genuine financial challenge. This was the case of a 60-year old woman and several others. In her disappointment, she complained:

*“Paying 2 cedis every day is too much. If you calculate your expenditure on hostel for a week or two, you can use the amount to buy some drugs. It isn’t that I don’t want to sleep there but the money....”*

Other LCs also felt it is not right for them to pay for the use of the hostel since it was put up by government. They justified their reason on the ground that the services they provide prevent government from employing more health staff. A discussant in one of the focus groups justified their action for not using the hostel and said:

*“For me, it is not right for the government to put up a hostel and rent it to caregivers. We are helping the nurses to care for the sick. They must have a place for us so that when we are coming, we will only bring some bedsheets and just come to stay.”*

In relation to this complaint, the researcher sought the views of the health professionals on why they charge for the use of the place. One of the nurses found it amazing that the LCs complain about the two Ghana cedis charged being too much for them and exclaimed amidst laughter:

*“Two Ghana cedis! In a way, the room they are staying in is free. It is because of the utility bills that they are paying the 2 cedis. If they were to go to town to rent an apartment, it would have been more costly. The 2 cedis is just a token to pay electricity bills because some even use blenders, water heaters and water for flushing the toilet so I think the 2 cedis is not bad”.*

This assertion was echoed by one of the ward matrons. Like the nurse, she explained amidst laughter that the two Ghana cedis is a token for paying utility bills of water and electricity.

The third category of LCs who did not use the hostel also complained of lack of knowledge on the existence of such a facility. The two who said this explained that they were not told and did not also find out if there was a place like that.

In a follow up question, participants were asked if they knew the health implications of either sleeping on the floor or in the chair in the ward; on the benches at the OPD and any other places. The responses have shown that not even a single participant lacks knowledge on the negative

effects of their actions on their health. However, they were doing this for the sake of the sick believing that nothing will happen to them because God will protect them. Maame Wakye represents the rest of the caregivers in this regard:

*“I know sleeping in the chair will bring some side effects but God is in control. I am thinking about the welfare of my child hence I have to do this.”*

#### **5.1.b. We Have Our Own Challenges**

Lay caregivers, who used the hostel, were not without problems. They were also disturbed by mosquitoes. Unfortunately, in one of the female rooms, the fan was not functioning. The caregivers claimed the caretaker of the hostel told them ten (10) Ghana cedis was needed to repair it but as at the time of the interview, it had not been repaired. The LCs further complained about the unpleasant smell emanating from the Kumasi Ventilated Improved Pit (KVIP) built at the hostel. This is experienced each day towards the evening and even though complaints have been lodged with the caretaker, no improvement has been effected. Lay caregivers however, feel more secured and protected as compared to those who do not use the hostel. Figure 5.1. shows the picture of the visitors’ hostel and compound.



Figure 5.1: Visitors' Hostel

## 5.2. Categorisation of Caregivers

During the study, it became apparent that lay caregivers did not constitute a uniform group. They were therefore categorised by their social status and the strategies they adopted to render care to their sick relations. Even though their demographic characteristics were taken into consideration, the major differentiating criteria were the residential patterns they adopted and the degree of their involvement in care. It is important to provide brief insight into the socio-demographic characteristics of the caregivers. This is due to the fact that a person's social status greatly influences his social role and as far as caregiving is concerned, the demographic characteristics of the caregivers are important. The socio-demographic characteristics considered in this study include age, sex, marital status, relationship between the caregiver and the patient and the occupation of the caregiver.

As indicated earlier, a total of 32 individual interviews were conducted with lay caregivers in addition to two focused group discussions which were made up of seven and six members respectively. The ages of the caregivers range between 13 and 80 years.

In the Ghanaian tradition, care for the sick was the preserve of the elderly men and women. Whereas the women mostly took care of the personal needs such as feeding and bathing of the sick, men were responsible for carrying the sick to the health care facility or for lifting the sick from bed. The men were also actively involved in going to the bush to find herbs to prepare concoctions or decoctions for the sick. The head of the family was involved in determining the kind of treatment to be given to the sick (Senah, 1981). It was therefore, a surprise to the researcher to see some school-going teenagers in the hospital environment providing care for the sick. Even though Atobrah (2009) found among the Ga that children between ages 6 and 15 years were involved in the care for the chronically sick in the home, they performed menial work only. However, the children involved in caring for their relatives at the study site provided the major care needs for their relatives. Only two teenagers of school-going age were included in the study but some patients also mentioned their children in the basic school as responsible for their up-keep. The two schooling caregivers included in the study were below 20 years and aged 13 and 16 years, respectively. They were both caring for their mothers and they were both pupils in basic school who had abandoned their education to cater for their mothers because other older relatives were not readily available to cater for the patient. By the end of the field work, the researcher came into contact with ten schooling caregivers. Four participants were also in their twenties while eight were in their thirties. Five out of the 32 were also in their forties while eight were in their fifties. Three of the caregivers were in their sixties and two who aged 72 and 80 years respectively were also among the caregivers. With the continuous presence of children in

the care environment, the researcher can conclude that, in contemporary Ghana, care for the sick is no longer a preserve of the elderly as reported earlier. This confirms Atobrah's (2009) finding on children's involvement in care for the sick. These young ones were the main caregivers of their patients and were actually involved in the personal care needs of the patients. The only form of care which was not common with them was the provision of financial assistance to the sick. This notwithstanding, one patient mentioned that her 14 year old daughter either did laundering for people or begged for alms to assist her financially. The table below shows the age ranges of the caregivers encountered.

Table 5.1 Age of Lay Caregivers

Age Range	Frequency	Percentages
10 – 19	2	6.3
20-29	4	12.5
30-39	8	25.0
40-49	5	15.6
50-59	8	25.0
60-69	3	9.4
70-79	1	3.1
80-89	1	3.1
<b>Total</b>	<b>32</b>	<b>100</b>

Data from the field indicate that, the majority (27) of the participants were females. Only five were men. The large number of females found supports the findings of Goodhead and McDonald

(2007) that caregiving is seen as an aspect of the expressive work of females; hence caregivers were mostly female members of their families. Care for the sick can therefore be described as feminised and this may be attributed to the traditional roles women play in the Ghanaian society. Before large numbers of Ghanaian women were found in the paid work environment, most of them were home makers/keepers paying attention to their children, husband and the other elderly members of the family. If they were engaged in any economic activities at all, they were either helping their husbands on the farms or engaged in petty trading. Some however, learned basic vocations such as dressmaking and baking which they normally inherited or learnt from their mothers or other family members. Care for the home therefore became their main preoccupation.

The educational level of these caregivers was rather low. While some had no formal education, most of the caregivers did not go beyond secondary education. It was only two out of the 32 who went beyond senior secondary school level: the majority ended at the Middle School Level or Junior High School level. This rather low level of education placed these caregivers in the informal sector of the economy and thereby giving them the opportunity to take up the caring responsibility at the hospital while the highly educated caregivers work in the formal sector and send money for the care of the sick. This assertion of formal sector workers providing financial support to the sick was expressed in the responses of some caregivers. A thirty-seven (37) year old male farmer caring for a nephew who had a snake bite had this to say:

*“My brother and I are responsible for the care of our nephew but due to his work, he does not come in the morning but comes at night. I stay from morning to evening and he stays with him in the night. He buys the medicines and I also take care of his personal care needs”.*



Of all the 32 individual participants, only one worked in the formal sector as a teacher. Twenty-eight were informally employed as tailors, farmers, petty traders, and ‘chop bar operators’ among others, while the remaining three were students. Nine caregivers mentioned farming as their occupation. They cultivated food crops, fruits and vegetables while eleven were traders and sold items such as second hand clothing, oranges, “kenkey”, “hausa koko” and confectionery. As a result, their source of income was not only irregular but also inadequate. As self-employed, they had enough time to themselves and did not need permission from anyone before leaving the work. This also enabled them to respond to the needs of their sick relations on time. Twumasi (1988) indicates that the socio-economic position of the caregiver affects the condition of health of the family members. This implies that, if a caregiver’s occupation is so demanding that it takes him/her away from the home, that caregiver will not pay much attention to the sick. Even though the self-employed caregivers’ quick response to the needs of the sick benefits them, it affects the self-employed caregiver negatively in that his/her absence from work affects his/her source of income and a long absence from work may also result in loss of customers.

The researcher wanted to find out whether a caregiver’s marital status negatively affects caregiving. This is with the assumption that married people may not easily leave their marital homes to care for a sick relative apart from a spouse and children. From the study, four different marital statuses were identified among the caregivers. These were single/never married, married, widowed and divorced. The majority of the participants were married and only six (6) were never married. However, their marital status did not have any negative significant influence on their caregiving role as some left their spouses at home to care for their sibling and other relatives. Some caregivers explained that their marital status did not have any negative influence on their caring responsibility because caring for the sick is not only morally desired but also a



biblical demand (Matthew 25: 36). A forty-seven year old kenkey seller was caring for her brother even though the brother was married. When asked why she rather than her brother's wife was caring for her brother, she explained:

*"Please, he has a wife but she is a teacher and also, all her children are very young. They were living in Accra together when my brother became ill and I requested my brother be brought to me here. I also have children who are schooling and a husband but because he is my only brother, that is why I have dedicated myself to cater for him".*

As reported earlier, literature reveals most caregivers to be relatives. There was, therefore, the need to find out the relationship that existed between these lay caregivers and the patients. It is a common belief that, with globalization and nucleation of the family system, coupled with migration, urbanisation and industrialisation, the extended family system has weakened and, care for the sick has also changed from being the responsibility of extended family members to other social forms of social relationships (Atobrah, 2009). A question was therefore posed to find out the relationship that existed between the caregiver and the care recipient. The relationships found between caregivers and the sick were framed within the context of consanguinity. Non-relatives refers to caregivers who do not have any blood relationship with the patient. Such relationship included friends, neighbours, work colleagues and church members. The table below gives a summary of the relationships identified in the study.

Table 5.2 Relationship between Caregivers and Patients

Relationship	Number of respondents	Percentages
Daughter	12	37.5
Mother	7	21.8
Son	3	9.4
Spouse	4	12.5
Siblings	2	6.8
Other relatives	3	9.4
Non relative	1	3.1
<b>Total</b>	<b>32</b>	<b>100</b>

Out of the 32 caregivers, 12 were daughters, three were sons, seven were mothers, four were spouses, two were siblings, and three were other relatives while only one was non-relative. This non-relative was a student caring for a colleague student as she saw it her moral obligation to provide surrogate care for her friend in the absence of close blood relations. She expressed herself in the following words when she was asked why she decided to stay with her friend in the hospital environment.

*“Because she is my friend and we are in school and there is no family member around, I have to care for her even though the family members came from Accra to visit and went back”.*

The high number of relatives or family members confirms the findings of Blum & Sherman, (2010); Oliver et al., (2013); and Wacharasin & Homchampa, (2008) that informal caregivers are mostly family members and caregiving is also seen as work for the female. Two out of the three

sons were caring for their mothers while the remaining one was caring for his father. The four spouses interviewed were all wives even though two patients interviewed were being cared for by their husbands but these husbands were not available for interview. According to NHC (1998), informal caregiving is characterised by relationships and social expectations. Caregiving is also strongly grounded in the relationship between caregiver and recipient. van der Geest (1972) indicates that people acted the way they did because of the network of social relationship between them. This implies that lay caregivers have some personal or intimate relationship with the sick they cared for. This finding shows that even in the face of globalisation and modernisation, family members still play a major role even in the life of their sick relatives. The assertion by some scholars that globalization and nucleation of the family system, coupled with modern professionalism and old school associations have weakened the extended family system and have changed the structure of care for the sick to include relations other than close blood relations is however not supported by this study because majority of the caregivers were family members.

From the foregoing discussions, different categories of caregivers were identified during the field work. The study therefore classified the caregivers into two broad categories. The first broad category is based on the residential pattern adopted by the caregivers during their stay in the hospital. The second is based on the degree of involvement in provision of care for the patient.

### **5.2.a. Residential Pattern of Caregivers**

Based on the residential pattern adopted by these caregivers, two types of caregivers were identified. These are resident and non-resident caregivers. Resident caregivers were relatives, who due to the long distances between their homes and the hospital, decided to move and live in

the hospital environment to be able to care for the sick. A focus group discussant expressed this view in the following words:

*“Where I come from is very far and going home and coming back everyday will cost me much money. If I should be going to and fro every day, where will the money come from? So, I have decided to stay around and care for my relation.”*

Other resident caregivers also expressed similar views.

The second group of resident caregivers were those who considered the condition of their patients as serious and needed much attention (that might not be given by the professional) and therefore could not stay away from the hospital environment. This view was expressed by twenty-four (24) out of the 32 participants. Some discussants also shared this view. The health condition of the patient therefore greatly influences the presence of some of lay caregivers in the hospital environment. One caregiver indicated:

*“As for me, my mother’s health condition will not allow me to be far away from her. When she was at the Casualty Ward, I was there with my sister and the least thing that happened to her they (health professionals) came to call us. The two of us were rotating in attendance but now that she is in the ward, I sleep in the ward while my sister sleeps at the OPD.”*

A discussant also supported the view expressed by the above caregiver and added:

*“The patient may be in a poor condition. For example, wounds on the skin such that the nurses may not be willing to touch the patient but you (caregiver) whose relative is sick will have sympathy for the sick person so that he/she will not die. Sometimes, the nurses will give you gloves to wear and attend to the patient by feeding, bathing and doing all other things for him/her to recover quickly. We know that all that we are doing were the responsibility of the nurses sometimes ago, but today, it is not like that.”*

The non-resident caregivers are those who due to the close proximity of the hospital to their homes and non-severity of the health condition of their patients, decided to stay at home but came to the hospital regularly to care for their sick relations. It must be noted here that, these category of LCs also rendered similar if not the same services to the in-patient just as the resident caregivers did. It must be noted that even if caregivers lived near the hospital, the severity of the condition of their relative compelled them to live within the hospital.

### **5.2.b. Degree of Involvement in Care**

The second major category of caregivers was based on the degree of involvement in care provisioning. Three types of caregivers were identified within this group namely: permanent or regular caregivers, non-permanent or irregular caregivers and shift caregivers. The regular or 'permanent' caregivers were those directly involved in the day-to-day care of the patient and were always found in the hospital providing one form of care or the other to the patient as and when the need arose. These caregivers were resident or non-resident. The main feature that distinguished these caregivers from others is that, they were always available to provide care to the sick and they were the people whose names were mentioned by the patient if asked to name a caregiver.

The non-permanent or irregular caregivers were those who were not always involved in the day-to-day care of the patient but provided certain services to assist the sick. They may provide things like money for the upkeep of the sick, food and sometimes may even visit. According to Whitlatch et al. (2001) and Sackey (2009), visit is a form of care.

Another class of non-permanent caregivers were those who ran shift in providing care. This category of caregivers did not only provide food, money or visit but actually took part in the

provision of personal care needs of the patient. These were relations who felt it was their responsibility to care for the patient, but due to circumstances beyond their control, could not be available all the time to provide the care needed. They, therefore, negotiated with other family members regarding visitation and care. This phenomenon was commonly observed during the field work as most patients especially those with severe health conditions had more than one caregiver. A 54 year old woman described vividly how she ran shift with her sister in caring for their aged mother:

*“Our mother’s condition is such that, she cannot do anything for herself. The nurses only come to check her pressure, sugar level and temperature; all other things are done by us. As I sit here, my sister is with her and when she is tired I will go to replace her, this is how we have been doing it daily.”*

To another caregiver, the need for funds resulted in the sister leaving for Accra to work for money. This is how she puts it:

*“We were two at first; one was with our sick relative for the night. When my sister was with her, I went and washed the things for her. After that, I went to sleep at the OPD so that when my sister needed me, she could come in to call me for a change over. My sister is gone to Accra. Both of us cannot continue to stay here while our work is left unattended to because we spend a lot of money here. Pampers for instance, cost us so much and we buy other things as well. We pay if we want to bathe, and we eat as well. Hence she must go and work for money while I remain with the sick.”*

The main difference between irregular or non-permanent and shift caregivers is that while the former did not necessarily get involved in the day-to-day care of the patient, the latter did. The categorisation above is however at variance with Rosenthal, Marshall and Macpherson’s (1980) finding where nurses classified family caregivers into three: visitor, worker and patient. This classification is based on the role the caregivers play in the Euro-American context. According to Ward-Griffin and McKeever (2000:91), “a relative who either spent considerable time at the

hospital or who was perceived to interfere with the nurses' preferred work style or the control of their work environment was considered to be a "problem" by the nursing staff. When family members were seen to be slipping out of the visitor role, they were cast into either the role of worker or patient"

### **5.3. Conditions of Sick Relatives**

As medical ethics does not permit health professionals to disclose the condition of patients to outsiders (eg. the researcher), a question was asked to ascertain the caregivers' knowledge on the health condition of their sick relative. Nine participants showed clear lack of knowledge on the health condition of their patients. The following are some of the responses indicating lack of knowledge on health condition. While Asuboiba indicated, she did not ask the nurses of the diagnoses, Maame Suhumaa stated:

*"As at now, there has not been any report from the doctor. We were asked to do a scan outside the hospital but after the scan, a relative of mine claimed she (the patient) needs to undergo surgical operation, but due to her age (she is reportedly 100yrs) she will be given some medication until she is well."*

Lack of knowledge on the patient's condition supports previous studies carried out by Atobrah, (2009) and Hynes et al., (2012). Hynes et al, indicate that lay caregivers express frustration concerning the fact that fuller explanations are not given them by health professionals about the disease trajectory and management and this often results in fear, isolation and anxiety.

Like the caregivers, some patients also expressed lack of knowledge on their own health conditions either because they were not told by the doctor or they did not ask. They could therefore only describe their condition on what they felt. However, Clause B under the patient's right of the Patient's Charter of Ghana affirms the right of the patient to know of his/her health

condition. The clause states: “The patient is entitled to full information on his/her condition and management and the possible risks involved except in emergency situations when the patient is unable to make a decision and the need for treatment is urgent”. Patients and caregivers’ lack knowledge on their health condition due to the super and sub-ordinate status that the health professional and the health consumer occupy in the therapeutic process. In the politics of the therapeutic encounter, the professional feels sharing knowledge on the patients’ health condition means letting go of the power he/she holds on the encounter. The health professional therefore holds on to the professional knowledge which gives him power over the health consumer. Abraham and Shanley (1992:82) described doctors as “authority figures”. They advanced their argument that doctors engage in this behaviour to ensure that their authority and expertise remain unchallenged. This knowledge power inequality does not exist between doctors and patients or their caregivers only but also between doctors and nurses. The scholars added that “the establishment of open communication between nurses and patients is at the centre of effective nursing intervention” (Abraham and Shanley, 1992:105). As a result, doctors and nurses should disclose the health condition of the patients even in terminal cases as this will make the patient arrange their affairs and prepare for death.

Based on observation, experiences of patients and caregivers within the hospital context and findings from this study, conclusions may be drawn that in Ghana, health consumers lack the courage to question health professionals on their health conditions. This may be due to two reasons. One, the doctor works within his/her jurisdiction or appropriate domain within which he is acclaimed to have the knowledge and expertise. The health consumer, therefore, feels the health professional knows it all and questioning him or her may be regarded as uninformed intrusion into an area the consumer is incompetent to handle. In some cases this intrusion may



affect the type of treatment given the consumer. This behaviour of health consumers is often not encouraged by health professionals. The researcher was once told, “You teachers are too known” when suggested an alternative course of action regarding her own treatment. To the professional, the client knows nothing. This action of health professionals is rooted in ethnocentrism and power relations that exist between the two. As Senah (2002) reports, patients feel they are treated like “tako” (rag), by the doctors in the therapeutic encounter.

The second reason is the lack of knowledge on the basic rights of patients. Simply put, the difference between the professional and the lay caregiver lies in the level of knowledge each possesses on health conditions and fear of victimisation account for lack of knowledge on the health condition of the patient.

The second group of participants, showed some level of knowledge on the health condition of their patients but were not very sure of the scientific authenticity of this knowledge. The following are but some of their responses in this regard:

*“He has a heart problem and dizziness and when we came, he was given blood transfusion. We were told he will be given another one today”.*

Stroke was the most commonly visible sickness identified during the study. About 10 caregivers were caring for patients with stroke. Two were also caring for HIV Aids patients. Other conditions included swollen legs and a few severe malaria patients. As Nyongator (2007) argued it is necessary to provide health information and education to households to increase uptake of health services.

#### 5.4. Types of Care Provided

Lay caregivers provide different forms of care for their sick relatives. This section discusses the various forms of care they provide. When LCs were asked what they do for their sick relatives, one of them responded:

*“The gate is opened every morning at six and before that time, I am already there. When the gate is opened, I go to fetch water, give him oral care, get warm water and give him a bed-bath. I always use “pampers” (a disposable diaper) for him, so I have to change the “pampers” if it is soiled. I prepare tea for him, after which I give him the medicine to take. I then dress him and after that, I am out of the room. At twelve noon (12:00pm), I go back to him with a heavy meal and when it is three pm (3:00pm), I go back to give him food again. After all these, I come to sleep at the visitor’s hostel ...This is what I have been doing for the past forty days that I have been here...They make us do everything even the drugs are sometimes given us to be given them.”*

Statements like the above set the pace to investigate the types of care these lay caregivers provide for the patients on admission at the KCH. From the study, the types of care provided are grouped under the following: emotional, financial, physical, spiritual and other cares needed. The types of care identified in this study fit into three out of the four forms of social supports identified by House, (1981). According to House (1981), people provide instrumental, emotional, informational and appraisal support to others. Instrumental support deals with the provision of tangible needs and services, emotional support deals with the provision of trust, empathy and love while informational support involves the provision of suggestions, advice, and information needed for therapy management. The fourth type of support which was not evident in this study is appraisal support and it involves the provision of information that is useful for self-evaluation purposes. Lay caregivers provide these care needs in order to restore good health to the patient. This act of LCs is consistent with Homan’s success proposition which states that a person is most

likely to undertake an action if such action brings more rewards. In this situation, restoring human life is most rewarding to the LCs. Reblin and Uchino (2008) and Frohlich (2014) also report that social support whatever form it takes, has a positive impact on health outcomes emotionally and socially.

Lay caregivers expressed different ways in which they provide emotional support to their loved ones on admission (Aziato & Adejumo, 2014; Feeney & Collins, 2003; Hemsley et al., 2008; Ishikawa, Roter, Yamazaki, Hashimoto, & Yano, 2006). To some LCs, engaging the patient in conversation diverts the patient's mind from his or her condition and feels comfortable while to others their mere presence in the hospital milieu coupled with the attention given all the time, does the magic. In her response to the type of care she provides for her husband, a thirty-eight year old lady said:

*“Sometimes I engage him in conversation to take his mind off the illness. By doing so, he will be emotionally stable. I sometimes tell him not to worry about his condition because God will heal him as I always pray for his quick recovery.”*

Similar views were expressed by many caregivers where their main purpose of engaging the patient in conversation is to console, comfort, encourage and give hope which is believed would facilitate the recovery rate of the patient. Linking communication with health, Mattson (2011) indicates that social support can lead to improvement in several areas of health and wellbeing and communications that help people cope with a situation makes people feel better about themselves. The direct effects theory of social support also indicates that loneliness is associated with poor health hence giving companionship to the sick help in the improvement in health (Uchino, 2004).

Others also intimated that their mere presence around their patients provided much emotional relief while the contrary did not augur well for the patient. The following are the words expressed by some participants on the issue of providing companionship to their sick relations:

*“...he finds comfort even to see me around him. I sometimes console him. Sometimes, he tells me to tell the doctor to discharge him but I also tell him to wait patiently till he fully recovers before he is discharged.”(A 72year old mother)*

A middle aged woman (53) could not find words appropriate to describe her presence in the hospital. She simply explained everything in these words:

*“She is in SHS and coming on admission here is a worry. She is also worried because her classmates are learning and she will lag behind in her studies. It is not her wish to come here (hospital) so I was telling her that God will do everything for her to get well early enough to join her mates. I comfort her so if I were not with her, how will I give her hope or words of encouragement? You have to come closer to be able to give such encouragement.”*

In order to ascertain the emotional benefits patients derive from the presence of their caregivers in the hospital environment, patients were asked to state the benefits they derive from their caregivers. A 30 year old orange seller, Asem, lamented:

*“Sister, for me I feel sad that I have a mother, who has given birth to me and when I became sick, she refused to care for me but I have given all to God (patient sobs). When I see other patients with visitors, I become very sad. If they (family members) had come, it would have given me comfort; and even if I will not survive, they would have given me “awere kyekyre” (encouragement). If they come around to encourage you to eat and the way they relate to you, if you were thinking about your condition, it will give you some relief”*

Similarly, Mununi who is a nursing mother could not hide her emotions while talking with the researcher:

*“When people visit me, it makes me feel I have people who think about me. Somebody will come and give you something and another will come just to visit and they are all benefits. I will think a lot if they do not visit me and the thinking alone may kill me.”*

The statements made by these two patients indicate depth of emotional care provided by lay caregivers in facilitating the rate of recovery. Engaging the patients in conversation is to make the patients forget about their condition. Asem’s statement shows the extent of disappointment in her mother’s inability to visit her. This reinforces the moral obligation and responsibility kingroup members have towards each other.

Accessibility to good health care delivery in terms of affordability and availability has become a common parlance, in the political campaigns and manifestoes of most political parties in Ghana in recent years. This idea of accessibility is like a mirage or better still, an utopia to many average Ghanaians, especially the rural poor. As a result, many family members would have to pool their resources to care for a sick relative if they care for his or her life. As ill-health takes the sick from his or her sources of income, especially those in the informal sector of the economy, financial assistance from family members cannot be ruled out of the numerous cares these lay caregivers provide for the sick (Sackey, 2009). A down-hearted mother who was caring for her daughter expressed her feelings as: “Please, if she has no money, I must go and borrow money to care for her and when she is well I will work and pay the debts”.

One of the young men, being the only child of the mother only went religiously to describe the financial assistance he gave his mother who suffered from stroke, as a miracle. His words were, therefore, carefully selected to describe the miraculous ways he was finding money to assist his

mother. These are his words:

*“I will first of all say that it is by God’s grace and not man that I have been able to get things done for my mother. It has been a miracle throughout our stay as at now. Sometimes, they (doctors) will request for certain medicine or laboratory tests which do not cost less than one thousand two hundred (1200) Ghana cedis. Even if you are a bank manager and you have so much money, it will get finished but I have been sustained by God’s grace. I am the only child of my mother so I provide money to meet these huge expenses.”*

The other lay caregivers also expressed similar views on the financial care they provided for the sick. However, some caregivers did not provide the money themselves but rather, their siblings or family members provided the money through them. Foa and Foa (1980) indicate that man’s resources could be put into socio-emotional and economical uses, while economic ones are tangible and are often financial, socio-economic ones deal with social and self-esteem needs of the person and also expresses how valuable a person is. These needs are very essential for the recovery of the sick.

In support of what these caregivers have said, most patients indicated that their caregivers supported them financially. This, according to the health professionals, is what is actually expected of family members to do for their sick loved ones. Provision of financial support in this study is, therefore, seen as a moral obligation of caregivers towards the sick.

The physical cares provided by lay caregivers were expressed in the form of bathing, feeding, washing of clothing, and positioning the patient in bed. These personal care needs are supposed to be done by the nurses or by patients themselves but due to their ill health, patients need assistance in performing these functions. Other studies carried out have shown that family members provide most, if not all the physical care needs of the patient (Stavrou et al., 2014).

Bathing the patient is one of the most common physical cares provided by almost all caregivers. Ablution was given either in the form of a wet bath where the patient was taken to the bathroom and bathed or in the form of a dry bath commonly called bed-bath. Bed-bath is given to patients who, due to their condition cannot go to the bathroom and are therefore cleaned in bed. To Maame Maamenti:

*“I assist her to bathe. She can’t bathe on her own. In the morning, I boil water and if it means giving her a bed bath, I do or take her to the bathroom and bathe her. Can a nurse do all these for her?”*

Similar views were expressed by other caregivers and were confirmed by the care recipients (the patients). The health professionals also did not deny the fact that lay caregivers help them in bathing patients due to shortage of staff.

Even though the hospital provides food for in-patients, some caregivers were there just to ensure that their patients got the best food they wanted. This is because the hospital’s food was not served on time. Besides, the hospital serves only breakfast and lunch and also the food did not meet the individual tastes of patients. For example, even though some patients (like diabetics, patients with stroke and the unconscious patients) who are fed through the nasogastric tube were on special diets, nurses did not pay much attention to special patients. During the study, one of the nurses and the DDNS explained that special diets were prepared for special patients if the kitchen staff was informed. However, since the special patients were few, their family members often provided their meals.

Patients are normally served their first medications between six and seven in the morning, while breakfast from the hospital kitchen was served between eight-thirty and nine o’clock in the morning. Even though some medicines are supposed to be taken before meals, the hospital food

is served sometimes two hours after medication and since taking medicine on an empty stomach for more than an hour has serious effects on the health of the patients, these lay caregivers provide food for their patients on time. This is what one of the caregivers said concerning the time food is served:

*“The hospital serves food, but the food does not come early so in the morning, I have to look for some porridge for her before their meal comes.”*

Apart from the food not being served on time, caregivers and patients complained about the number of times meals were served. It was a common knowledge that for good health, every adult is to eat balanced meals three times every day. However, patients were served only breakfast and lunch and the lay caregivers were supposed to provide supper for their patients. The researcher therefore sought views on why patients were served with only breakfast and lunch and all the nurses interviewed including the DDNS said even though that was a source of worry to them, there was little they could do because the National Health Insurance Scheme makes provision for only the two meals.

In addition to the above complaints, the food the hospital kitchen served did not meet the taste of most patients, as a result, the patients did not eat it. Most caregivers complained their patients had lost appetite for food and as such, they were selective in what they take in to satisfy hunger. Some patients, even though adult, needed to be coaxed to eat. The hospital menu lacked variety; it was highly Spartan: breakfast was corn porridge (koko), rice water, or tea while lunch was meals from rice products or yam slice. These meals were however not served simultaneously to make room for choice. The researcher once witnessed a situation where light soup was prepared for those who were being fed through the nasal tube. Despite this, most caregivers provided food for their patients. The food was either prepared at the hospital environment or at home. The



resident caregivers normally prepared the food at the visitors' hostel in the hospital while non-residents prepare it from the house. A 48 year old wife, resident caregiver (who was the only formal sector worker during the study) has this to say:

*“The hospital authority brings them food, but he does not like their food. So I prepare his meals. I prepare the food he likes for him and I normally eat the hospital food to avoid waste”*

Some caregivers also brought food prepared from the home by themselves or by other family members. A 60 year old dressmaker and an aunt to the patient said:

*“Family members sometimes bring food from the house (Somanya) but she may call me and demand certain type of food and I buy them for her. For example she may request for kenkey, tea or koko and I have to buy it for her and I sometimes buy drinks with biscuit for her.”*

Those who buy food by the road side or from chop bars were very visible in the study. Buying food became mandatory rather than a choice due to inadequate time available to cook and also due to easy accessibility to these types of food.

*“The last time food was served, she did not eat and I could not force her so I went to buy kenkey for her. Since we came, she has always been requesting for kenkey with pepper sauce but the hospital does not serve that. I buy food for her.”*

The above statement and similar others, justify why caregivers provide food for their patients. When asked whether the food was not good, the responses were both positive and negative. A 54 year old woman who came all the way from Accra to provide care for her mother has this to say:

*“Oo its fine. They do it well. They know how to cook. I’m a cook; I cook for some white people. Their food is nice.”*

A thirty-eight year old caregiver rather had a contrary view to what was said earlier. To her, the hospital meal was not very good in quality; she described it as being “mass production”. She simply puts it this way:

*“The hospital sometimes serves tea and rice porridge but since it is mass production, they will give him plenty but he cannot eat because it may not be as rich in nutrients as I do it for him. If it is rich in nutrient and he takes small, it is fine”*

As ill-health renders most patients incapacitated, there was the need for family members to feed some of them. Feeding is the second highest physical care lay caregivers provide for their relatives in this study. As many as seventeen (17) individual participants mentioned feeding of their relatives as the reason for being in the hospital.

*“mmm ... Some patients wouldn't eat so you have to force them before they eat the food. And if no one is with her, she wouldn't eat when it's given to her. When you are with her you can force her to eat and that is why I am here.”*

Concerning those who are fed through the nasogastric tube, this is what a discussant said:

*“Sometimes, if you don't force your way through, the patient will not be attended to. For example today, I had to force for my patient to be fed...this concerns patients who are fed through the tube, if you don't force the nurses they will not feed the patient. As the man (referring to the only male participant in the focused group discussions) has said, if it is time for the patient to be fed, they will not do it unless you are there to force them”*

Reacting to the above statement, health professionals explained that, some caregivers were impatient. They expected the health professional to attend to their patient even if they had other patients to attend to. Sometimes, feeding may delay either because the caregivers did not bring the food on time or the kitchen food was not ready. However, they (caregivers) felt that the moment the food was brought the nurse should leave everything and attend to their patient immediately.

Lifting patients from the bed and turning them, especially, the bedridden ones was also one of the physical care needs provided by these lay people. This task does not come without its negative effects on the caregivers. This demands the use of physical energy hence most of the caregivers complained of bodily pains and tiredness due to the frequency of this physically demanding job. This was due to lack of lifting equipment and adjustable or movable beds and chairs. These bedridden patients, if not frequently repositioned in bed, may develop bed sores. Sometimes, there was the need to raise them from the bed either to be fed, bathed or to change their clothing and diapers and beddings.

Lay Caregivers also did the laundry of their patients. While some washed the things in the hospital, others who live around sent them to be washed or other relatives came for them to be washed. A young man in his mid-thirties who was caring for a mother suffering from stroke could simply say:

*“I was the one feeding, bathing her, and washing her clothes; I mean everything I have to do for her I did it.”*

Figure 5.2 shows some of the washed items on the drying line at the visitor’s hostel



Figure 5.2: Hostel Laundry Section

Provision of spiritual care was not left out of the numerous kinds of care these lay caregivers provide for their patients at the KCH. According to Waliggo et al (2006:233), “spiritual care of the sick is very important in Africa. If well done, it can make a real difference to the sick and their families. Spiritual care should be provided not only in hospitals and other health care settings, but should in fact be a required subject for all pastoral agents and health care workers (HCWs) at every level of African society”. Taking the Ubuntu culture for example into perspective, the authors indicate, caring is a core value and has associated values such as sympathy and helpfulness and empathy which are necessary in palliative care. They furthered their argument that the basis of spiritual care is compassion, making oneself available for the patient in times of suffering and this gives the sick hope and comfort.

Some caregivers mentioned that, they were in the hospital praying for their patients. Whereas some prayed alone with the patients, others called pastors and prayer warriors to join them pray in or outside the hospital environment.

Senah (2002:47) quoted van der Geest to have said ‘the ward was not merely a place of practising medicine, but also a “place of worship”. The typical Ghanaian hospital ward experiences “the continuous visit of praying people”. This statement is true about most of our hospitals today and KCH is no exception. Hardly will someone visit a sick person without saying a word of prayer before leaving the ward.

Spiritual care for the patients was provided not only by these lay caregivers but also people the researcher refers to as “Hospital Ministers” (HM). Some authors called them “faith healers”. According to Twumasi (1975) faith healers (both males and females) are often leaders of revival, sectarian or African-based syncretic churches. Apart from church service, some of them operate healing sessions and they use the bible, holy water and prayer sessions to help patients who come to consult them. They deal mainly with social, psychological and psychosomatic problems. Cockerham (2007:174) also defines faith healers as “people who use the power of suggestion, prayer and faith in God to promote healing. Denton (1978), states that two basic beliefs are prevalent in faith healing: one form of belief supports the idea that healing occurs primarily through psychological process and is effective only with psycho-physiological disorders. The other belief is that healing is accomplished through the intervention of God and constitutes present day miracles. The difference between the faith healers of Twumasi (1975) and Cockerham (2007) and the “hospital ministers” is that, whereas faith healers operate their own healing centers, the “hospital ministers” use the hospital environment for healing and are not necessarily owners of healing centers but are members of religious denominations. They preach

and pray for the sick in the hospital environment. The HMs operates with the two basic beliefs as identified by Denton, (1978).

During data collection, both patients and caregivers mentioned the services of the hospital ministers as vital in the recovery process. Any casual visitor to the Koforidua Central Hospital early around 5.30am, might easily mistake the hospital for a church hall. The hospital ministers loudly preach and pray for patients, caregivers and the hospital administrators. From the OPD to the wards, one would find a minister, preaching and praying. Their messages are aimed at giving hope and assurance to the sick and their caregivers that God will grant their heart's desires. Long life, good health, knowledge and prosperity are requested for the staff of the hospital. Songs are sung aloud at the OPD as some of the caregivers join the ministers to sing and pray. However, in the wards, church hymns are sang undertone in order not to disturb the seriously ill. However, sometimes, some patients also join in singing the songs. The researcher sought the views of both patients and lay caregivers on the operation of these "hospital ministers". In response, various opinions were expressed. Even though some participants appreciated the work of these HMs and felt they should be assisted to continue the good work they were doing, others also felt that even though they were playing a crucial role, they should not be assisted financially since God's work is not profit oriented and that God himself will reward them. The following were some of the views expressed by the caregivers:

*"Those people are spiritual. For me, I cannot see into the spirit but God has endowed them with that gift to see beyond the ordinary. I am nowhere near them; so I have been praying to God to give them the strength to do the work. If it is possible, the hospital should make them (hospital ministers) part of the care delivery system."* (Maame Mienka)

Another caregiver echoed what Maame Mienka said concerning the usefulness of these HMs but did not agree with their inclusion in the health delivery system of the hospital. She explained:

*“Ooo they are doing well. They have dedicated themselves to prayer. They give pieces of advice during their preaching when they come...I don't think they should be employed by the hospital. God's work is not done like that. As I speak with you, when they pray out of their will, then God opens doors for them elsewhere. That's the real work of God and sometimes they receive gifts from people when the people are touched by their messages.”*

Many other LCs praised the HMs for the works they are doing. They came morning and evening to pray for the patients.

In addition to the above mentioned care that lay caregivers provide, they also assist the patient in doing certain things such as attending to nature's call:

*“I assist her to go to the toilet and urinal. I prefer staying with her because as we speak, she has soiled herself so I am only waiting for the nurses to come and remove the drip to enable me change her diapers.”*

Similar concerns as above were raised by other caregivers. However, other caregivers also intimated that, they run many kinds of errands for their patients. These include taking them to the laboratory, getting their prescriptions from the pharmacy or buying the prescription from outside the hospital premises, taking them to other departments such as ECG and X-ray among others.

The following lay caregivers describe what they do for their patients as follows:

*“For about close to a week that I have been here, I collect any prescribed drug for her. If she is asked to go to the lab, I accompany her. I go for her folder. I console her sometimes that it shall be well. I do all these things so that she will feel comfortable. This is why I am around her to share in her pains and worries.” (Odamea)*



Similarly, a 67 year old man, Opanin Kweku, who was attending to an elder brother with genitor-urinary problem, described his assistance to his brother:

*“I assist him a lot by taking him for scan, and x-ray; I buy drugs and do anything that he will need me to do for him. For instance, the day we came to the hospital, it was very difficult to get a folder for him because there were a lot of people there and my brother could not queue for the folder. I forced my way through and prepared everything for him before we saw the doctor.”*

Figure 5.3 shows a picture of a lay caregiver pushing a patient in a wheel-chair, a task which in the normal run of hospitals falls within the domain of nurses and their auxiliaries.



Figure 5.3: A Patient in a Wheel-Chair and a Lay Caregiver

Other caregivers indicated that they assist in administering drugs to their patients. This assertion was made by a sizeable number of participants. One of them, Kukua intimated:



*“The nurses and doctors come to administer medicine. However, sometimes, they will ask you (the lay caregiver) to administer the medicine. If there’s no one by the patient, they give her the medicine and sometimes they ask of the caregiver and if there is someone around they (health professionals) teach them how to administer the drug. Sometimes they watch you do it (give her the medicine) before they leave. At other times, they tell you to give it to the patient after eating, so if the patient has not eaten, then you have to go and find food for the patient before administering the medicines.”*

With reference to Kukua’s statement, the researcher sought the views of one of the nurses on why the caregivers were involved in the administration of drugs, a task supposed to be the preserve of the professionals. One of the HPs explained:

*“Ehm, if it is a task or something we want the relative to know, we direct them. We give them specific instructions as to what they should do. Even while we are doing the work, we still instruct them because if the individual (lay caregiver) should take that patient home, it is what you taught him/her here that he/she will practice at home. So, as we are assisting them or they are assisting us, we give them specific instructions depending on the patient’s condition and what is required of them...A lot of them cooperate. Just a few of them forget whatever instruction you gave and go contrary to it but a lot of them cooperate...”*

One of the ward matrons gave a further explanation adding that, some of the medications were taken at home and if the caregivers were not involved in their administration at the hospital they might go home and do the wrong thing. She cited the example of people who are fed through the nasogastric tube and those who are given injections every day. She further explained that they do not have enough workers to follow the patients to the home to continue with the treatment and that if the LCs did not get used to the task in the hospital, they could not do it at home. It is, therefore, for these obvious reasons lay caregivers were involved in performing some of the professional tasks.

This notwithstanding, lay caregivers also monitor the infusions (drips) and oxygen fixed on their patients. Some caregivers complained that some nurses did not pay attention to patients when infusions were set on them. Sometimes, the oxygen would run out but no one would be around to replace it for the patient. A young man, Baako, who was attending to his mother bitterly lamented:

*“The one I asked to care for my mother informed me my mother has been pulling off the oxygen and the drips so I should come. When I came, there was no oxygen on her meanwhile she was on medication because she was in coma for such a long time. I reported everything to the nurses about how my mother was pulling all these things, but the nurses did not respond immediately as they should have, considering the fact that my mother was just gaining consciousness... Meanwhile, when my mother removed the oxygen in the night, the second caregiver did report to the nurses. The nurses said they would come later to see to her, but they did not come. When she (second caregiver) detected that the patient’s breath was going down, she went back to them and they said that it was not yet time for them to work and that was the reason for their delay in attending to the patients. One of the ward assistants came to the scene but she could not do anything, and she left because she knows nothing about what was happening to my mother. When I got closer to my mother, I realised her breath was going down and I had to force the nurses to attend to her. Since then, I realised that things are not going on well here at the hospital.”*

Similar complaints about the nurse’s inability to properly monitor the medications fixed on the patients were made by other caregivers. The researcher, therefore, verified from the health professionals their views on these allegations. Some nurses denied knowledge of such happenings while others admitted that negligence is common with every human institution. One health professional defended this act in these words:

*“Well, I can talk for myself; I cannot talk for my colleagues. When I am on night duty for example, the things that I normally do before I go to rest for the two to three hours is that, I make sure all infusions are infusing well. If I see that the number of milligrams left to finish is not much, I usually set an alarm so that in one or two hours it alerts me to change the infusion of that individual but as a human being, sometimes there may be situations in which I may forget. I might not know that the infusion is finished. For example, in our side ward over here (pointing to sideward), and where I am sitting, it will be difficult for me in the night to be able to check whether the infusion there is finished or not. There is no way...so it is possible there are some infusions that might run out and I might not know. Mostly, I make sure if the infusion is not much, I alert myself through an alarm. Some of the patients also need to be blamed. Immediately you go away, they open the “given set” because they want the infusion or whatever drug is fixed on them to get finished as early as possible so they open it to flow more than the recommended speed. So while you have timed yourself, within four or six hours it will get finish earlier because he /she had opened it. By the time you get there, he will tell you it got finished long time ago but you did not come to check on him. Meanwhile you also know the infusion will get finished at the time you have set. Sometimes, it is not our fault. I agree that some of these things are possible...but sometimes the patients also have to be blamed.”*

A further explanation was given by one of the ward matrons when she said that these incidents were possible due to staff shortage and caregiver impatience. To her, the ward was understaffed but most of the patients on admission were the critically ill who needed much attention. However, since every patient is so dear to the caregiver, most caregivers feel that more attention should be paid to their patients forgetting that other patients are equally important to their caregivers. A little delay in attending to a patient is therefore met with bitterness and insults from some caregivers.

It may be deduced from the above statements made by the LCs and the HPs that even though the patients’ decision to seek health care at the hospital supports one of Parsons’ sick role

expectation that the sick ‘seeks technically competent help in getting well’ this expectation does not hold true in this study because lay care services are needed in the hospital setting to be able to provide the needed care for the patient.

Realising that lay caregivers were providing care such as administration of medication and handling patients’ folders to get prescriptions which tasks were supposed to be done by the health professionals, the researcher probed further to find out whether these lay caregivers were aware of the roles of the health professionals in the ward.

From the data collected, thirteen (13) participants showed clear knowledge of the role of the health professional in the ward while the majority lacked knowledge of the role of these health professionals. Those who knew the role of the nurses were further asked why they decided to provide care which was supposed to be provided by those who were in charge and various responses were given, some of which are as follows:

*‘I know the work I do is supposed to be done by the nurses but once you have come, you must also assist. The nurse can only do a little. My mother might have soiled herself but the nurse will not have time for her. Maybe, if you are not there she (the nurse) may do it but once you are there you have to do it.’*

In a further interaction, these lay caregivers believed they need to assist the professionals in order to provide proper care for their patients. While some felt they were helping the nurses, others thought they are helping the patient; yet another group considered the services they provided as helping both the nurse and the patient. This notwithstanding, some lay caregivers simply saw their efforts as complementing the efforts of the professional caregivers.

Investigating further, LCs were asked what they would have done differently if they were caring for their patients at home. According to most of the participants, they would have rendered

similar if not the same services at home just as they are doing in the hospital. If there would be any difference at all, it would result from the freedom and comfort of their home environment. According to a 60-year old dressmaker, Awonye, (who was caring for her niece):

*“I will do the same thing at home just as I am doing here. If they give us medicine and the time I should administer it in the morning, I will do it and if you take the drug without food you will not get the strength so I will force her to eat. In the afternoon, I will do the same and do same in the evening.”*

Awonye’s statement supports Radstake (2000) report that in Ghana, the difference between home care and hospital care can be small as lay caregivers provide personal care needs while nurses provide medical needs. Hospital care is therefore similar to home care; the only difference is in quantum of resources available. Whereas the hospital may be equipped with more resources including orthodox medicine, the home may have only folk medicine but no orthodox medicine.

The various forms of care provided by these caregivers and the patients’ readiness to accept these supports reflects Parsons’ (1951) sick role expectations as discussed under the theoretical framework.

### **5.5. Challenges Facing LCs in the Hospital Environment**

The challenges facing lay caregivers are numerous. These challenges are the difficulties they go through while caring for their patients. These difficulties are the conditions either present or absent in the environment which interfere negatively in their daily activities. Kasuya, Polgar-Bailey and Takeuchi (2000) indicate that, caregiver’s burden is a multidimensional response to physical, psychological, emotional, social and financial stressors associated with the caregiving experience. The challenges found in this study are of two main groups. These are the institutional

and home. The institutional factors are those factors which are either present in or absent from the hospital environment which made caregiving very difficult for the LCs. The institutional challenges include inadequate accommodation, lack of access to information, poor environmental hygiene, inhuman treatment and others. The main home factor was inadequate finance. These challenges are multi-dimensional in that some lay caregivers were confronted with multiple institutional factors in addition to the home factors which are mainly financial.

### **5.5.a. Institutional Challenges**

In addition to the institutional factors hindering lay care giving is inadequate accommodation or place of rest. This has however been mentioned earlier in this chapter. In addition to this, was the reported inhuman treatment, lack of access to information and poor environmental hygiene. A caregiver reported thus:

*“The security men are also worrying us. I just picked up a quarrel with one before coming to you. I was angry and told him it is not our wish to stay in this environment. They are impolite when talking to us. They sometimes push us and compel us to say something we might later regret. They sack us like animals.”*

Some actions of the health professionals such as the one described in the above statement was what the caregivers described as inhuman treatment. This complaint came second on the list of the challenges facing these caregivers in the KCH. This treatment was meted out to them often by the hospital security men. For want of words to describe their experiences, lay caregivers simply said: “won reteetee yen (they are worrying us), “won reha yen, (they are disturbing us) won rebuyen (they don’t respect us) and won repam yen” (they are sacking us) were the most common vernacular expressions used. To the majority of the participants, even though the security men had the duty to sack them after visiting hours or when they hang around, the way

they went about it was very inhuman. One of them lamented:

*“Sometimes you may be in front of the ward to keep an eye on your patient, but the way they treat you....does not show any respect. Look at me, Last, I leaned against a pole and the security man called me “hey! hey! hey!” (derogatory) and when I turned, he asked me not to lean against the pole or else it will break. I asked whether I am a bulldozer to break a pole. Is this body (turning her body around for the researcher to view) heavy to pull down a pole? However, he sacked me and I came here” (visitor’s lodge).*

Another member of the group retreated and lamented bitterly on the disrespectful way they were treated by some of the hospital staff. She had a word of suggestion to those who could influence the life and decision of these workers and said:

*“One thing that workers of this hospital must be made to understand is that all the fingers are not equal. There are some that are short while others are long. Caregivers are not carpets or it isn’t that they don’t have any work to do. Take for example this elderly woman (pointing at a 75 year-old woman in the group), a nurse or security man who could be her grandchild can call her “hey” stand up from this place. When you complain, they will tell you “dwuma bia ni emu brofo” (every work has its “English language” meaning every profession has its rules). They shout at you “go go”. Even if they are bosses at their workplace, they could call the person with politeness and say it is not right to do these things here but the health professionals do not have any respect for anybody. For the security men, the least said about them, the better. They talk to people without showing respect. They should respect us for we are also human beings”.*

Several of such complaints were brought forward during data collection. The actions of the workers were described as very bad and disheartening. Some advised that the health professionals including the hospital security men should learn to be patient with the LCs since they were also human beings and need to be recognised as such. This need for recognition is what Maslow (1954) termed self-esteem needs and is one of the basic needs of man.

The above notwithstanding, some caregivers indicated that when one treated the security men well, they would also treat one well. “Treating well” here means that, one must motivate them by giving them either cash or kind and also respect their office. To the LCs, if one did any of these, one will be in their good books.

Other LCs who lamented on how they were sacked from the wards when the doctors came on visitation felt such an act was wrong. They argued that they were with the patients and knew what was wrong with them and would be in a better position to describe the condition of the patients to the doctor better than the nurses. The health professionals however expressed different view on this. According to one of the nurses, it is true that the LCs may have certain information about the patient that they (HPs) may not know. However, since health issues are supposed to be confidential and the presence of these LCs in the ward cannot guarantee this confidentiality, they are sent out. One of the medical officers also indicated that the presence of the LCs interfered negatively in their work. The position of the health professionals finds support in the Patient’s Charter of Ghana. Clauses G and H focus on patient’s right regarding their privacy and confidentiality of information on patient. In more specific terms, Clause G reads: “the patient has right to privacy during consultation, examination and treatment”. According to Clause H “the patient is entitled to confidentiality of information obtained about him/her and such information shall not be disclosed to a third party without his/her consent...”. The nurse, therefore, suggested that if any LC has any special information about their patient, such information should be made known to the nurses on duty so that they would inform the doctors when they came on visitation. Further, they added that, LCs also have the right to request or book an appointment to see the doctor attending to their patient and lodge any complain they have. Expressing her view on this issue, one of the medical officers added that when the patient



is unconscious and certain information is needed about him or her, they contact the person whose name is given to the hospital as responsible for the sick.

A study carried out by Washington et al (2011) on information needs of informal caregivers of older adults with chronic health conditions report on lack of access to information as one of the challenges facing caregivers. In this study, caregivers showed lack of access to information on the health condition of their patients, and lack of knowledge on their basic right of access to information. As discussed earlier in this chapter, some caregivers lacked knowledge on the actual problem of their patients (Hynes et al., 2012; Toscan et al., 2012). When asked why they did not ask the HPs about the health condition of their patients, some said they were afraid while others said they had planned to ask at a later date. Some however, stated that they did not know they could ask. For those who could not ask for explanations, the reason was purely on power relations: they feel the professional has power which should not be interfered with. They also feared that interference might create hatred in the health professional towards their patient which may negatively affect the care that would be given the patient.

### **5.5.b. Environmental Challenges**

Environmental challenges included the inadequate number of washrooms and their poor sanitation status. The male and the female wards are 23- and 44-bed capacity wards, respectively. However, they have only two washrooms each for each of the wards. This notwithstanding, some of these LCs also shared this limited facility with the patients. This has resulted in pressure on the facility. Even though the orderlies of the hospital were often seen cleaning these facilities, complaints revealed that these places were not kept in the best sanitary condition exposing the users to opportunistic infections. In response to this complaint, one of the

ward matrons explained that even though they were working with limited number of staff, their staff was doing its best. She did not hesitate to add that they would take a second look at the complaints. It must be put on record that towards the end of the study, both the male and female wards were renovated to give aesthetic improvement to the working environment. This however, did not come with any infrastructural additions.

Even though the KCH cannot be described as generally unkempt, much needs to be done especially on the lawn near the visitors' hostel. LCs complained bitterly about the weedy nature of the place which serves as a breeding ground for mosquitoes and reptiles. Some said they feared passing there in the night for fear of being bitten by snakes. It must be noted that towards the end of data collection, the place was cleared of weeds. Caregivers suggested that the place should be sprayed with pesticides and insecticides to destroy the mosquito larvae as some of them went back home with malaria when initially they did not experience that condition.

Seeing patients die, absence of warm water in the wards, seeing patients with different and serious health conditions and lack of space for rest during the day were but a few of the other challenges confronting the LCs. One of the caregivers lamented on how dead bodies were sometimes left on the bed unscreened and observed that the way they were handled by the mortuary attendants was very disturbing. These were her words:

*“Seeing people dead and left on the beds on the ward is a problem because when they come to pick them to the mortuary, they throw them “gbugbum” (sound) onto the carrier in the presence of the other patients. I feel that since they have curtains in the wards, it would be better to screen off the dead so that patients will not see how the dead are treated. The way the dead are handled put shivers in patients.”*

Most caregivers use warm water to bathe/clean their patients. The wards however, did not provide warm water for these patients. Caregivers, therefore, had to buy hot water outside the ward and this they said cost them fifty (50) pesewas per bucket. When asked why the hospital was not able to provide warm water for patients, one of the nurses, explained that for about four years then, there had been no hot water provisioning because the electric heater was in a state of disrepair. However, the male ward had a kettle for making hot water for patients.

During the day, some LCs wanted to be close to their patients so that in case of any emergency, they will quickly provide the needed service, but they complained that provision was not made for them in this regard. The health professionals think that, the LCs' closeness to the ward was not necessary since the patients were in their (HPs) care. Thus, caregivers' plea for opportunity to be near the ward was often not entertained.

In the hospital where both the living and the dead cross paths, some caregivers complained of their encounter with spirits especially during the night. There were several anecdotal stories of this nature. A participant narrated one of such stories thus:

*“There are things in darkness. There was a sister who was sleeping near the gate because her mother was on admission. Suddenly, she realised that, there was a sister (stranger) sitting by her at around 12 mid-night. The things the stranger was saying frightened the caregiver and she started shouting and running and all the nurses and the patients were asking what was happening. She told them the stranger said she (the stranger) was a witch. The things that are happening in darkness....!!!.”*

The story above reflects the Ghanaian belief in the supernatural. “There are things in darkness” simply means that darkness/night is pregnant with spirits. The Ghanaian believes that there are the natural (physical) world which are the things that we can feel or see around us and the spiritual world comprises spirit beings which cannot be seen but are believed to have power to

bless or harm. Witchcraft, lesser gods, ghosts, ancestors and the supreme God are some examples of the components of the spiritual world. The belief in the existence of the components of the spirit world constitutes supernatural beliefs. The major implication of the beliefs in the supernatural is the fear it creates in its adherents which can impact the individual negatively or positively.

### **5.5.c. Financial Challenges**

Most participants reported financial difficulties as one of their biggest challenges. This finding gives support to a previous study carried out in Uganda (Emanuel et al. 2008). The financial challenge facing caregivers in this study has been alluded to in earlier chapters. As explained, most of these caregivers worked in the informal sector of the economy where their income was generally low and irregular. Their already low income status was worsened by the ineffective functioning of the National Health Insurance Scheme. This difficulty, according to some of them pushed them to access other health care regimes especially prayer camps and herbalists (Assimeng, 1995). Due to this, some came to the hospital with advanced form of ailments resulting in their being hospitalised.

These caregivers blame the Health Insurance Authority for their predicament. While some claimed that the scheme does not cover most of the treatment given to their patients, others felt it was rather not functional. Due to the high cost of treatment, some patients were even detained at the hospital for non-payment of bills. The case of Asem is an example. This will however be explained under patients' experiences in chapter 7. According to one of the Ward Matrons, the minimum bill that any patient who came to the ward with or without health insurance paid is one hundred Ghana cedis (GH¢100). Perhaps, the statement made by Maame Kanewu captures the views of all others on the status of Ghana's National Health Insurance Scheme:

*“The Health Insurance does not cover anything. We are just holding the card. It is not working. The Health Insurance that should help us is not working. Any time a medicine is prescribed and you go to collect it, you are told to pay first. Sometimes GHc1,200, and where can you get this amount? Some people came on admission here and could not get money to pay and as a result they died. A lot have died. We want to appeal to them to do something about the health insurance because it is not serving the purpose for which it was introduced. We pay for virtually everything.”*

It must be noted that it is not only patients who suffer from such financial predicament but the caregivers also. Even though eating three meals or better still a well-balanced meal is required for good health, some caregivers sacrificed their meals and fast because they did not have the money to buy food. Some eat once a day while some forgo their meals entirely. This however has its own health implication.

#### **5.6. Effects of Care on the Caregiver: Health, Work and Family Life**

It was necessary to take a look at the impact of care on the caregivers’ life. This is due to the fact that, caregivers may be workers, family members and social beings. As said earlier, ill-health in its severe form is disruptive and exacts a heavy toll not only on the sick, but also on their social network. In this regard, three major aspects of the caregivers’ life were investigated to find out how caring for their patients had either positive or negative impact on them. These three areas were the health of the caregiver, the work he or she does and the general social life with special attention paid to the status and the role in the family.

In the search for responses on the impact of care on their health, three responses came out clearly. From the data, it was clear that care impacts negatively on the caregiver’s health physically and emotionally or psychologically. However, few people claimed care had no negative impact on their health. The effects of care on the health of the caregiver is however

influenced by certain factors such as the severity of health condition of the patient, the degree of caregiver's involvement in care and the health condition of the caregivers themselves.

Physically, pains of any kind in the body topped the list. General bodily pains, headache, backache, pains in the waist and kneel joints were but a few of the complaints. Some experienced these pains due to the constant walking around the hospital in order to provide one form of care or the other and also due to raising and turning of the sick in bed.

Others also claimed their pain was caused by the absence of a comfortable place to rest. They therefore slept in any available place they found, be it on the bare floor, on benches or any abandoned hospital object.

Some lay caregivers did not hesitate to complain about the tiring nature of care for the sick. This tiredness could be caused by the frequent movement they undertook in the hospital or through the provision of various forms of care.

It was also found during the study that some caregivers were already sick before coming to the hospital to care for the sick. The story of a daughter caring for a mother is presented below when she was asked if the caring activities have any change in their health status:

*“You asked right. I was also not feeling well before she became sick. When I was sending her to the Suhum Hospital, I also went with my cards with the intention of seeing the doctor but upon arrival at Suhum Hospital, we were referred here. However, since we came, I have not had any chance or free time to even attend to myself for treatment. I just called one of my children to come and assist so that I can see the nurses for them to attend to me alongside my mother. I have decided that after my mother is discharged, I will return for my own treatment. All I could realise is that I am not all that healthy. Yesterday for example, everybody was happy using the fan but it was not in my favour just because I am not feeling well. When the fan is on, I have headache and sometimes, I*

*feel numbness in my hands so in the night when I realised everybody was asleep, I put all the fans off before I was able to sleep. Sleeping on the floor has negative impact on my health, but I have no option.”*

It may be deduced from this statement that people will help others when they realise that sick relations are in more serious health condition than them. This is because, apart from the example given here, other participants also complained of poor health conditions, but felt that the patients on admission had more serious problems which needed prompt attention. From this, the conclusion may be drawn that caregivers suffer from different forms of pains and tiredness while providing care for the sick.

Apart from the negative physical impact of care on the caregiver, they sometimes suffered from emotional impact of the care they rendered. While some caregivers were able to mention the actual emotional effects on them, others simply said the condition of their patients have greatly affected them emotionally. For lack of equivalent English translation, their emotions were captured as “ayem hyehye” (anxiety) and “adwendwen” (worry).

Another emotional expression was ‘Me yem hyehye mi’ (expressing high level of anxiety). This expression was very common in the stories of many participants. This shows how caregivers go through emotional trauma in providing care for the sick. The impact of emotional effect on the caregiver nearly resulted in the death of a caregiver who participated in the study. She said she was nearly knocked down by a vehicle because she was thinking about her friend on admission at the hospital. In her own words she said:

*“I have only been worrying about her and could not do anything. Yesterday for example, I was nearly knocked down by a car when I was coming in the morning because I was*

*thinking about her. Sometimes there was nothing I could do. I could not sleep. I sat down restlessly”*

However, some caregivers did not experience any negative effects. Some simply said God looked after them well. Baako described his experience thus:

*“Ah! My health is sustained by the grace of God. I ascribe all these to God’s grace. When my mother was admitted, I slept on the benches near the casualty ward because I was called upon by the nurses at any time to provide one thing or the other and all provisions were made by me single handedly. However, I have not experienced any negative change in my health.”*

The provision of care for a loved one on admission has resulted in some people moving away from their work environment to the hospital environment. As described earlier, this has resulted in different categories of caregivers such as ‘resident’ and ‘non-resident’ as well as ‘permanent’ and ‘non-permanent’ LC. To some of the participants, their presence at the hospital had a heavy toll on their work while others do not think that it has affected them negatively.

Nineteen (19) participants indicated that their work or source of livelihood has been affected negatively. The nineteen participants were those who were in the economically active group (of ages twenty (20) to sixty (60)). Even though these participants complained bitterly, one statement that was never missing at the end of their complaints was: “human life is more valuable than work”.

Some lay caregivers also complained that due to their presence at the hospital; their sources of income have been blocked resulting in financial difficulties. This was the case of informal sector workers who did not fear being sacked from work (due to their long absence from the work place) but fear they might have lost their customers to other competitors. Since they generated



their own income and no longer worked, some ended up denying themselves meals due to financial challenges. This is the story of a 27-year old lady caring for her sick mother:

*“When she was not sick, I was at home doing my work and feeding myself but here I am, doing no work and my source of income is blocked. Yesterday, I did not eat the whole day because I did not have money.”*

Similar statements as the above were made by some caregivers. Whereas the informal sector workers’ source of income was blocked which was a toll on his/her finance, the formal sector worker still maintained his/her source of income. However, the recipients or the beneficiaries of the services of these LCs (formal sector workers) were the sufferers. This was because instead of the workers going to work five days in a week, their presence at the hospital made them go two or three times. The statement made by a teacher in this study explains this better:

*“I do ask permission before embarking on any visit to the hospital. I attend school three times in a week. Taking a bus to school and getting another bus after school back to this place is a challenge.”*

In the case of the participant in this study, the day of the interview was her fortieth day at the hospital. The day her patient will be discharged was not also known. This caregiver’s commitment to the care of her husband and responsibility towards her pupils caused her role strain, a conflicting situation. The cost of the care provided by these lay caregivers may not be easily quantified but its negative effect may be long lasting.

If being a lay caregiver has taken someone from his/her community to another, what happens to the social life of that individual especially with regards to his/her status role? As shown in table 5.2, some caregivers are mothers, daughters, sons, spouses, siblings, other relatives and friends. These people might have other statuses with their respective roles as well. For example, a

daughter who is caring for a mother or father may be somebody's wife or mother. As they have taken on care responsibility, their commitment to their social roles and to the rest of the family members is affected. Caregivers expressed worrying views on the negative impact of care on their social roles. To most of them, since human life cannot be replaced when lost, they needed to sacrifice their other responsibilities towards the strong to care for the sick paying little or no attention to the adverse effects it might have on the strong.

*“My children are not grown-up. The eldest among them is a footballer. Someone even wanted to help him but because of his uncle's ailment, I could not provide the needed support for him. He's also in the house so I don't have anyone to help me. The one about to complete Senior High School is also at home. What worries me is leaving my work and my family behind. My children go through a lot and that worries me. Three days ago, I was informed that my grandchild was sick. I had to be commuting between home and hospital now and then. I always pray that God will see me through because he knows what I am going through”.*

The above statement was made by a 50-year-old kenkey seller, Sister Onua who was caring for her brother because the brother's wife was a formal sector worker in Accra and the children were not old enough for her to leave them behind. It is clear from the statement that the caregiver's absence from the home was having a heavy toll on her children's welfare. She has lost her source of livelihood hence cannot meet the financial needs of her children. For a daughter, Oyokoa, in order to care for her mother with stroke, her own four-year old daughter was left in the care of a co-tenant, while Maame Mekaa, a thirty-eight-year old woman caring for a husband had to leave her nine (9) month old baby in the care of her elder daughter, denying the child school attendance. This caregiver however sadly lost her husband five days after granting this interview. However, in the case of Oyokoa, the inability of her siblings to assist her has resulted in some sort of conflict between her and the elder siblings. She lamented that they were six siblings and

she was the last born, but when she called the others to assist, it was only the second born (a man) who came. She was very bitter about her elder sister's inability to come down when she heard of her mother's condition. As Ae-Ngibise et al. (2015) report, caregiving has negative effects on the social relationships of lay caregivers as they are unable to move about freely to interact with their colleagues.

The effects of caregiving on the caregivers is summarised in the words of Blum and Sherman (2010:244-245): "Family caregivers are suffering. They provide extraordinary uncompensated care that is physically, emotionally, socially, and financially demanding and results in the neglect of their own needs...The physical stress of caregiving can lead to significant physiologic changes and medical illness with a greater risk of mortality."

### **5.7. Option for a Paid Caregiver**

Due to the negative impact of care on these lay caregivers' work, health and social life, they were asked whether they would opt for a paid caregiver. The responses were with mixed feelings. Three reasons were given why they would or would not take paid caregivers.

The majority stated that they would not take any paid caregiver to care for their patients. Whereas some of the reasons they gave could be described as social, others were purely economic or financial. Social in this regard embraces the moral obligations as well. In relations to this, most LCs would not opt for a paid caregiver because they felt the caregivers might not be able to take proper care of their patients as they would have done. It is also not permitted for a stranger to see their relatives' nakedness. Some indicated that due to the attachment between them and their patients, they would go all length to do whatever the patient wanted but a paid caregiver might not have that patience. In addition to the fear that the patient will not be properly

taken care of, is the emotional trauma the participant will go through if his/her patient is left in the hands of a paid caregiver. Maame Kukua indicated:

*“I would not allow that, because I don’t think a situation like that can be well-handled by someone else. No one can take proper care of your patient. Even if he will do it, I will stand by to monitor how it will be done for my mother (silent), I can’t allow someone else to take care of my mother because she will not be happy. She feels happy to see me around. ... if it had not been me but someone else taking care of her, she would have been dead by now”*

To a 32-year-old man, the emotional trauma he would go through would not permit him to hire a paid caregiver. He simply said "me yem be hyehye me nti" (because of anxiety) I can’t hire anybody. I can’t sit at home to eat”

Other LCs would not take paid caregivers due to moral obligations to the sick. This was the case of a forty-four year old woman and many others in the study. From a moral perspective, they do not consider it morally right to leave a sick relative in the care of a stranger. To them, the best they could offer their dear ones when they were sick was to have time for them and see them as the most valuable thing in their lives. The participant therefore exclaimed:

*“The person who brought me into this world? What work is so valuable than her? I cannot hire anybody. I will do it myself. Even though school has re-opened, I left my children with my husband. I should have been there to care for them but unless my mum is healed, I am not going back. Even if she gets better, I will come from time to time to visit her because I am the eldest of the females and as such I have to take up the responsibility. Our last born who is the youngest has been assisting her for all this while so if she is sick and we the elders do not assist, it is not fine. I must assist. Even my elder brother comes here twice every day but as a man, what can he do? He also helps financially by buying the prescriptions”*

The other group of caregivers who accepted to take paid caregivers will do so based on reasons such as economic, condition of the patient and if it is a requirement. Economically, LCs would opt for paid caregiver only if the cost involved was not high. When asked how much they considered high or moderate, caregivers could not state any fixed amount. What most of them said was that, if the cost would not be beyond what they could afford they would accept the offer. Furthermore, some indicated that if what the contracted caregiver would charge would not be more than what they might earn doing their business, they might opt for their service. From this, it could be deduced that the cost involved in taking a paid caregiver was the main factor influencing these caregivers. This implies that if the cost is high (beyond what the individual can afford), they will prefer taking care of their patients. Similarly, some LCs will take paid caregivers in order to have time for their businesses. However, this is also influenced by the cost involved. This category of caregivers believes that if their continued stay in the hospital will cause them loss of money, taking a paid caregiver will be the best option. One of them said “enye nam na eyi nam? (Is it not fish that is used to bait fish?). This implies that if her stay in the hospital will result in losing money and paying a caregiver is equally losing money, then they are the same. However, she may be left with some money after paying the hired caregiver.

Furthermore, some lay caregivers also argued that a paid caregiver would be considered if only it is a hospital or institutionalised requirement.

Depending on the condition of the patient, some LCs suggested they would take paid caregivers. However, they would not accept the option if the condition of the patient is serious or critical (bedridden/unconscious) but if the patient’s condition is stable, they would do so. One thing that needs to be noted here is that, even those who accepted to take paid caregivers did not hesitate to say that they would continue to monitor or check on their patients. It may be deduced therefore

that, all things being equal, all participants will prefer caring for their patients rather than leaving them in the hands of non-relative paid caregiver.

Two caregivers were however not sure whether they would opt for a paid caregiver or not because they had to consult other family members.

### **5.8. Caregivers' Coping Strategies**

In the midst of the challenges, caregivers adopted basically three strategies in meeting their needs and those of their sick relations in the caring environment. These are (a) denying themselves some pleasures of life; (b) developing faith in God through prayers and (c) passing on the hospital identification card to other relatives who are not recognised by the health professionals as caregivers. This 'back-pass' is possible because the identification card did not bear the picture of the authorized carrier. This way, other family members desirous to visit the sick or relieve the original carer did so with ease while the authorized carriers were given the leverage to use their 'liberty' to engage in other activities.

In order to meet the financial needs of their sick relatives, some caregivers denied themselves food and good sleeping place. Some caregivers ate Spartan meals only once a day or fasted some days in order to save money. As indicated earlier, others also denied themselves good sleeping place (visitors' hostel) and slept in the open at the OPD and any available space. Even though these actions may seem pragmatic, the associated health implications may be very disastrous. Under these trying circumstances, the Ghanaian easily takes solace in the divine working power of God through prayers, a common strategy adopted by almost all the caregivers. They therefore rely on prayers offered by the hospital ministers, pastors and the leaders of their various religious denominations.

This chapter has presented the life of the caregivers and their experiences at the hospital. The next chapter discusses the reasons for engaging in care for in-patients at the hospital.

## **CHAPTER SIX**

### **FACTORS INFLUENCING LAY CAREGIVING**

#### **6.0. Introduction**

In the previous chapters, some allusions have been made to the forces that influence lay care giving. In this chapter, the forces are given in-depth articulation to deepen our understanding of the factors. Factors influencing lay caregivers to provide care in the hospital setting are multifaceted in nature. This is due to the fact that one lay caregiver may be influenced by more than one factor. The field data collected in this regard were aimed at answering the first two objectives of the study. These are to:

- a. Determine the socio-cultural factors that influence lay caregivers to provide care; and
- b. Investigate institutional factors that facilitate lay care giving

From the data, factors influencing lay caregivers spanned many areas of life. For a deeper understanding, the significant factors are highlighted below:

#### **6.1. Socio-Cultural Factors Influencing Lay Caregivers**

Lay caregivers' involvement in professional health care delivery would best be understood when the culture and the social context of the caregivers are taken into consideration. This is because caring for the sick though natural, has cultural influences. For example, in collectivist societies of Africa and for that matter Ghana, it is the responsibility of family members to take care of their sick loved ones until the persons was healed or died. Failure to do that by family members was a reproach to the whole family (Twumasi, (1975). This familial responsibility was influenced by cultural values that oriented the individual towards communalistic cosmology that



showed concern and care towards others especially those who are in need and appreciated the value of interdependence on family members. This ideology is reinforced by lack of national social support services that care for the aged and provide social security for individuals. However, even in individualistic societies such as the United States of America and the United Kingdom where children are independent of their parents at the age of eighteen and where there are some national social support services, it is evident that lay involvement in professional health care delivery is on the increase. Caring as a moral obligation, caring for reciprocity and caring as a tradition are the main socio-cultural factors identified.

#### **6.1a. Caring as a Moral Obligation**

The majority of the caregivers identified caring as moral obligation towards the sick. Some discussants of the FGDs did not hesitate to identify moral obligation as their main motivation for providing care in the ward. A study carried out in Thailand by Wacharasin and Homchampa (2008) identified moral obligation as a factor influencing lay caregivers in that country. For some participants in this study, the relationship that existed between them and the patient made it their moral obligation to care for the later. This relationship was influenced by some commitment towards each other. Children feel obliged to care for their parents because they were the ones who brought them into the world. A statement made by Maame Atta, a 49 - year old daughter confirms this:

*“I am here because of my father. He brought me into this world and I can’t leave him alone. I have to be with him until he recovers”.*

Similarly, Mekunu, a 53- year old man who was caring for his 96-year old father also indicated the father - son ties influenced him to provide care.

As caring for the sick is seen to be mainly feminine work, a further question was asked to find out why a man of his age would leave his family behind to stay with the father for over one week at the hospital. In his response, he indicated that he was the eldest son of his father. Also, even though his father divorced his mother, and re-married his new wife refused to take up the care responsibility. A study conducted by Feeney & Collins (2003) with 202 couples from the State of New York and California, on motivations for caregiving in adult intimate relationships revealed that inability to care for sick or aged partners is influenced by the caregiver's lack of skills for the task, dislike for distress, lack of concern/responsibility and lack of time to mention but a few. The researcher therefore investigated further to find out which of the factors identified by Feeney & Collins (2003) influenced Mekunu's father's wife. When asked why his father's new wife was not with him, this was what the participant said:

*"His wife was with me at the Roman Hospital (St. Joseph Hospital) but she refused to follow me here because she has to take care of other things including her farm. I also told her I have children and I have to work and cater for them but the woman did not listen. Because he is my father, I have left everything to follow him here for treatment."*

In a further response, he explained there was no known quarrel between his father and his new wife, but the new wife had a ginger farm and she decided to go and harvest it else, the ginger will get rotten. This new wife's behaviour could be interpreted to be influenced by lack of time and concern/responsibility. This is because from Mekunu's statement, the father's wife was with him when he was first admitted at the St. Joseph's Hospital also in Koforidua. Her inability to follow up to KCH will therefore be described as lack of time because she had to attend to her farm. However, this wife's behaviour is at variance with that of most participants in this study. They, see human life as more valuable than anything. These participants, would therefore, sacrifice all their resources including sources of income to care for the sick. Her behaviour can therefore be

attributed to lack of concern and responsibility towards her husband. The behaviour of this wife also contradicts Attobrah's (2009) finding among the Ga that wives are able to care for their husbands with chronically ill condition for a long time than husbands do. She reports that even if the man did not treat the woman well while healthy, the moment he becomes sick, the wife puts all those things behind and focuses on providing better care. Men however, give up soon when the health condition does not improve within the shortest possible time. In a follow up question the caregiver was asked why his sisters could not take care of their father and he again explained:

*“My sisters are old but it is not every responsibility that you shift to young ones. I am the eldest of my father's children and it is my responsibility to care for him. You, as the eldest would have to do this to make sure everything goes on well.”*

From this statement, the caregiver's ideology of primogeniture accounted for his care responsibility. Being a divorcee himself (Mekunu), he intimated that his children were with his sisters and he feels that if a man is sick a man rather than a woman should care for him.

Based on the mother-daughter relationship, Maame Mienka who was caring for her daughter but received no visitor from home after spending one week at the hospital did not hide her emotions on why she felt was her moral obligation to care for her daughter:

*“She is my daughter so I have to care for her to recover quickly. Look (calling for the researcher's attention), I have a family and my daughter is sick but nobody follows. I am here caring for her. She is mine”.*

As far as the relationship between the caregiver and care recipient is concerned, other LCs indicated they found it morally obligatory to care for the sick in the absence of other potential caregivers. The case of Norvi who is a student friend to a patient is an example. She indicated:

*“I have to do it because she is my friend and there is none of her family members here. I know that these people (referring to health professionals) will not do everything for her, especially fetching water for her to bath”.*

With the above statement, it may be deduced that in the absence of a consanguineous relation, people outside the kingroup can provide care for the sick. The experience of some patients such as Mununi attests to this fact. Mununi was being cared for by the daughter of her father’s friend.

Another factor which LCs considered to be a moral justification for caring for the sick is the age of the patient. This response is common with LCs who were caring for the elderly (above sixty (60) years). According to these caregivers, it is morally wrong to leave the elderly sick to suffer his/her plight in the care of unrelated family caregivers. The explanations given were that: the aged are already physically weak. Their already weak strength is worsened by their poor health condition. Leaving such a person without a regular family caregiver will be morally wrong (Janzen, 1978). This is what a 53- year-old woman caring for her mother has to say:

*“With her age, I feel it is my responsibility to care for her because the nurses do not come here often. Whether she eats or not I have to do everything”*

This expression is seen in what Meeker (1971) termed ‘rationality’. By this, people use logic to ascertain the possible consequences of an action and measures through which people could achieve things that are of value to them. Even though Meeker admits that people do not act rationally, we may deduce from the responses given that providing assistance of whatever kind to the sick due to his/her age is based on the logic that the aged need help and acting so is considered logical. Similarly, a social exchange theorist, Homans (1974) also indicates that exchange relationship is influenced by rationality.

Another group of caregivers who could not give any specific reason for caring, simply stated that since the person was sick, they owed it a moral obligation to provide care, and it is immoral to abandon the sick. This implies sick people need help and must not be left alone (Janzen, 1978/1982; Twumasi, 1975).

In relation to the above responses a further investigation was done into who was responsible for the care of the sick in the family. The responses given are many and varied. These include: social tie, abusupanin (family head), order of birth, extended family, sex, proximity and money. Concerning the social ties that exist between the patient and the caregiver, the following formed part of the responses. To some LCs, a parent should be responsible for the children and children be responsible for parents. Similarly, a husband should be responsible for his wife and a wife responsible for a husband. This was the view of Maame Suhumaa and many others:

*“If it is a mother who is sick, then her children are to care for her. At first, when your mother is sick, her relatives would come in to help, but now as the world is changing, it is the children’s responsibility even till the point of her death. If by God’s grace she regains her strength, it lightens the burdens on the children”.*

The statement made by Maame Suhumaa depicts social change in care for the sick in contemporary times. She indicated the world is changing and as a result, care for the sick has shifted from the domain of the extended family members to members of the nuclear family. However, some participants also mentioned the head of the family as responsible for the care of the sick. The family head (“Abusupanin” as in Akan and “Fomemetsitsi” among the Ewe) plays a major role in the life of his members. Traditionally, he sacrifices to the gods and ancestors on behalf of his members. He performs other functions for family members such as naming ceremonies and seeks good health for his members. In the traditional Ghanaian home, no

seriously sick family member, is taken to a place for healing without the knowledge of the Abusuapanin (Senah, 1981). However, in contemporary times, this may not be the case. This may be attributed to factors such as formal education, urbanisation, industrialisation and others that make the individual economically independent from the extended family. During data collection, some participants mentioned the head of the family as being responsible for the health needs of his members. One of the participants who was caring for a brother indicated that she reported her brother's ill-health to the head of the family and he helped initially in getting blood donor for his brother. However, when additional blood was needed, the head of the family complained he did not have money. This implies the head of the family can only be responsible for care of his sick members when his financial situation can afford it. Inadequate funds will therefore put limitation on the family head's function. Wealthy members of the society will therefore not depend on family heads for their health needs.

Closely related to the head of the family as a person responsible for the sick are other extended family members. This consists of grandparents, aunties, uncles, cousins and the other members of the kinship group members. Maame Suhumaa and Awonye for example indicated that members of the extended family were supposed to care for the sick but they did not hesitate to state that these days, things have changed hence nobody depends on the extended family so much again.

Another factor that influenced the responsibility for care according to the LCs, is primogeniture or the order of birth/age. To some, the eldest of the children should be the one responsible for providing care to the sick. The example of Maame Maamenti and Mekunu earlier and many others confirmed this assertion. In support of this, Maame Ga explained:

*“If you are the first born, and you don’t even have money, you have to bring the young ones together to raise some funds. I am the eldest among them so I’m caring. If I don’t have money, I will tell the young ones to pool their resources together.”* (A53 year old woman)

Gender is another factor that influences care. Whereas to some, when a man is sick, a man should care for him, the majority gave the support to the view that women should be in charge of the sick. The explanation given is that women are generally more patient than men since they are mothers. Their sympathy toward the sick is more than that of a man. Other studies carried out elsewhere as stated in the previous chapters support high levels of women’s involvement in caring for the sick. Based on this, the researcher concludes that, this has accounted for the large numbers of women present in the hospital environment; everyday provision of care is therefore feminised.

Proximity to the sick and money were also mentioned to influence who takes responsibility for the sick. Some caregivers asserted that, the degree of consanguinity to the sick should be the major determinant of who should provide care for the sick. To caregivers such as Anyina, Oyokoa, Asuboiba and Suhumaa, their degree of blood relationship with the sick influenced their decision to taking up the care responsibility. Other caregivers also thought that since care for the sick is influenced by the availability of money, those who have money in the family should be responsible for the sick. This view is captured in the title of Senah’s book “Money be Man” (Senah, 1997). This view is that irrespective of all other factors, good health care cannot be provided without money.

In most cultures around the world and specifically in the Ghanaian culture, there is an unwritten moral code of conduct which regulates the behaviour of people regarding what is acceptable and

what is not acceptable behaviour. As stated earlier on, the sick must not be left alone [Twumasi, (1975), Akrong (2009) of Ghana, Jansen, (1982) of Central Africa and Michinga, (2011) of Zimbabwe]. This implies that in some African countries and specifically in Ghana, it is an unwritten tradition that the sick person needs companionship which must primarily/traditionally be provided by close family members. With this background, some lay caregivers saw their care services to the sick even in the hospital environment as something that tradition demands of them. These ideas were manifested in some of the responses LCs gave as factors influencing their decision to provide care. When asked why they should hold unto an age old tradition, LCs indicated that society will mock at them if they do not follow their relatives to the hospital. Society's perception about the behaviour of LCs influenced them greatly as some of them even indicated it made them not to take a paid carer. The following two examples may throw more light on how tradition and societal perception influenced their involvement in care provision. A 72-year old mother has this to say:

*“They will mock at me very much. Some will say this woman refused to send her own child to the hospital. Whether the child will survive or not, some will say if I had attended to her, she would have survived while others will even say this woman does not have money so she could not even send the child to the hospital. Some will even go to the extent of saying that I am not a good person” (Hajia)*

To buttress what Hajia had said, Medin added:

*“They will say a lot. They will describe you as someone who is heartless and this also implies that you do not have any good character. Even you, the individual will realise that what you are doing is not right. (A 40-year old wife)*



### 6.1b. Caring for Reciprocity

*“Asie yina asi vana” (hand go hand come) and “nsa benkum guare nyinfa na nyinfa so guare benkum” (the left hand washes the right and the right hand also washes the left)”*  
(Ghanaian Proverbs)

The wisdom behind the above proverbs is found in most Ghanaian ethnic groups. Traditionally, most Ghanaians believe the best thing anyone can offer the other is to reciprocate the assistance received from others. The researcher can say with confidence that these days, people accompany others to funerals, weddings, naming ceremonies and the like with the motives that the recipients of such good gestures will reciprocate when they are also in need. Others also give donations at these functions with the belief that the act will be reciprocated. It is, therefore, not uncommon these days to hear people lament when their good gestures are not reciprocated. Those who give with the intention of getting it back in another reciprocated form will therefore not give if their good gestures are not reciprocated by others (Emerson, 1976). People who do not reciprocate for one reason or the other are often said to be ungrateful. This study discovered reciprocity in the statements made by some caregivers. Asuboiba expressed her reciprocity to her mother this way:

*“My mother suffered greatly for me. She gave birth to me and took care of me until I am old. If she is also sick, I have to care for her”* (A 27-year old daughter).

In a related statement, a sixteen (16) year old student, Akola, attending Junior High School (JHS) had to abandon her education to care for her mother. The statement below is her motivation:

*“As a child, if your mother is sick, and you are in school, you have to seek permission and care for her. She bears the cost of your living and if she is sick and there is nobody to care for her, you need to ask permission from school to stay with her. It is right and obligatory to do that for your mother, so I ought to”*

This statement indicates that Akola's reciprocity is influenced by cultural norms of values and obligation. When asked why no elderly person other than her was caring for her mother, she explained that her mother (the patient) had three other siblings but two were outside the country and they were responsible for the hospital bills. The one in Ghana with her mother was also sick and another family member was caring for her. Attobrah (2009) also found that among the Ga relatives abroad remit home money for the care of the chronically sick. Even though she was not the eldest of her mother's children, she is the second child and a girl so had to be present at the hospital because the eldest was a male. This affirms feminisation of care as noted earlier. This action by LCs confirms Cropanzano and Mitchell (2005) idea that social exchange relationship is influenced by rules of reciprocity. According to Cropanzano & Mitchell (2005: 875) "reciprocity in kind is probably the best known exchange rule" and that an exchange requires a bi-directional transaction. From the data collected, elements of the three forms of reciprocity; reciprocity as a moral norm, reciprocity as a folk belief and reciprocity as a transactional pattern of interdependent exchanges identified by (Cropanzano & Mitchell, 2005) were observed.

From the discussions above, a conclusion may be drawn that people will provide care for the sick as a payback for something good the recipient might have done for them. This form of reciprocity is influenced by social exchange. This finding supports the findings made by Sackey, (2009) when she studied the family networking and relationships in the care of the seriously sick in Ghana using the Fante residents in Accra and Cape Coast as case study.

Airhihenbuwa and Webster (2004), studied the influence of culture in African contexts of HIV/AIDS prevention, care and support and indicated a culture-centered approach to prevention, care and support is increasingly recognised as a critical strategy in health care delivery. Culture is therefore important in understanding health care delivery and lay caregiving. The socio-

cultural factors influencing lay caregivers give support to Leininger (1991b) culture care theory which indicates that for health professionals to provide better and holistic care for the patient, it is important for them to understand the culture of the patients.

## **6.2. Institutional Factors Influencing Lay Caregivers**

The institutional factors influencing lay caregivers in this study refers to factors that are present or absent or are imagined to be present or absent from the hospital. These factors are those that negatively interfere with the provision of quality care for the sick. From the data gathered, three major institutional factors have influenced the caregivers. These are shortage of staff, attitude of health professionals and inadequate supply of logistics. The researcher considered the issue of food not a major factor because even if the hospital should provide three meals a day, some patients will not eat it and caregivers will readily provide alternative sources of food for them.

### **6.2a. Quality of Care**

In addition to the institutional factors influencing lay caregivers is the issue of negative attitude of some health personnel towards patients. These attitudes according to the LCs are the behaviours that health personnel exhibit at the work place which negatively impact on the health of the patients. From the data gathered, the negative attitude is manifested in negligence of duty and lack of interest in the job. Many caregivers stated that some nurses do not pay proper attention to the patients in the wards especially at night. This has resulted in the untimely deaths of some of the patients. As reported earlier, proper attention is not paid to medication especially with monitoring of infusions and oxygen. Ramatu, one of the patients indicated:

*“The problem I have with them (nurses) is that, when they set the infusion on you; they don’t monitor it very well. Sometimes, the infusion will run out and when you even call them, they will be tossing you up and down.”*

Additionally, as a result of the absence of nurses in some ward cubicles, some patients are left to their fate when in need of help. In the absence of other patients who might be a bit better health wise to assist the seriously ill, the latter goes through undue hardships. Some complaints of caregivers will best explain this point:

*“This morning, I went home and I thought the nurses will attend to her (my mother) in my absence but they did not. In an attempt to urinate, she fell three times and by the time I came back from home, she was on the floor because she was not strong enough to walk. I came to raise her from the floor and put her in bed”*

The above statement was made by a 55 year old woman caring for her mother. This incident happened on the 22<sup>nd</sup> of January, 2016. The agony and anger in which this caregiver expressed her emotion was strong enough to tell the researcher that something was not going on right. The researcher therefore investigated further to find out whether she lodged complaint with the health workers. In her response she added that a nurse came to serve her mother with medication and she told her that the patient fell from the bed. The nurse in response told the lay caregiver it was because she did not come back early from the house to take care of the patient so the patient was looking for her and fell. This patient was an elderly woman suffering from mild stroke as a result could not move about freely. If the response of the nurse is something to go by, then, the health care system must make provision for the formal involvement of family members in care delivery at the hospital. The sad thing about what happened to this patient was that as a result of the fall, her face got swollen and one of the patient’s children brought some ice block from the house to be applied on the swellings.

Another caregiver, Maasem, bitterly complained:

*“These nurses do not take proper care of patients. If you don’t come round, they will leave the patient unattended. If she soils herself, they won’t mind her. She will be in it until a relative comes. When we are not here, “waa we ni tua” (judge it yourself). Today, this woman (pointing at a patient on a bed) fell from her bed and the nurse was asking her if she could get up. Let me use this as an example (still pointing at the patient on the bed whose caregivers were not around). Look at this bed, look at how things are scattered around the patient. She has urinated but no one is concerned about her. It is very, very bad. None of her relatives is around and if you feel you have brought her to the hospital and left her alone, the nurses will not mind her. For all you know, they (health professionals) will facilitate her death.”*

This caregiver however, lost his patient five days (19/01/16) after granting this interview. Other LCs also attributed this negative attitude of some health professionals to the many and frequent dead bodies they have seen. This they claim makes them see human beings as “nothing”. Perhaps, the views expressed by the caregivers find confirmation when Cockerham (2009) described hospitals as “deathhouses”. Negligence of duty was reported in the news by the Registrar for Medical and Dental Council of Ghana. According to the doctor, negligence of duty has accounted for the numerous death cases recorded in the wards these days (TV3 News, 16<sup>th</sup> February, 2017). Table 6.1 provides data on the death toll of patients who died in the first – five months of data collection. This number covers only those who participated in the study and whose death occurred at the hospital. In February, 2017, fifteen (15) deaths were recorded in the female ward alone.

Table 6.1 Death Toll of Patients within the First-Five Months

Name of Lay Caregiver	Relationship of Patient to LC	Date of Interview	Date of Death
Caregiver 1	Husband	12/01/2016	16/01/2016
Caregiver 3	Mother	14/01/2016	19/01/2016
Caregiver 14	Son	18/02/2016	02/04/2016
Caregiver 20	Mother	11/04/2016	22/04/2016
Caregiver 21	Brother	11/04/2016	01/05/2016

Related to the above, some LCs described the actions of some of the nurses as showing lack of interest in their job. This category of LCs think the HPs are interested in money therefore took nursing as a profession and not the love for the job. Some also described their behaviour as showing sign of tiredness and lack of sympathy towards the sick. In her agony, the 38 year old wife lamented:

*"You could see that the nurses feel they are tired of the work they are doing and cannot pay enough attention to only one person. It is tiredness. There are some who do not have "abadae" (sympathy) for people and they behave as if they are tired or you are worrying them so much. What pains me most is that, there are things they do not do for the patient but if you want to do it for him, they sack you."*

Lack of interest in the job was echoed by one of the senior nurses interviewed. Her words could be summarised in the above statement. She advised that, we (the public), must pray hard or else a time will come when we will have to leave our homes and take intensive care of our patients on admission. To her, the nurses available today are not committed. Their behaviour could be

sometimes disturbing and unethical. This is because most of them did not choose to do nursing but they were forced or given protocol admissions at the nursing colleges. According to her, she interviewed a few of the young nurses when they came to the ward on attachment and what some said was that they were asked by their parents to do nursing. To others, they were in the house when they were told to prepare to go to college because they had been offered admission. She further added, nursing is a vocational calling and a difficult vocation and profession. If people are now being forced or due to the presumed/perceived lucrative nature of nursing, others are pursuing it, then the future of the health profession in Ghana is being compromised.

Even though most of the lay caregivers feel the nurses are not giving off their best, many others also think differently. Some LCs praised the nurses for meeting their expectations as they were seen helping some LCs to care for their patients. Some described the nurses at KCH as better than nurses at other hospitals.

*“They (HPs) assist a lot. Even this morning, I was giving my patient (patient is fed through the tube) water when a nurse assisted. Even when my patient urinates in the chamber pot, they sometimes empty the pot”*

Others who could not find words most appropriate to describe the attitude of the HPs simply said ‘they are good.’ One thing the researcher noticed about the responses caregivers gave about the attitude of nurses is that those with seriously ill patients described the attitude of nurses negatively. This is not surprising because most of such LCs in this category lost their relatives. Those whose patients were with mild conditions described the nurses in a positive light.

### **6.2b. Shortage of Staff**

Shortage of staff in this study means the number of nurses who are required to run the wards on a three-shift basis is inadequate. Both health professionals and lay caregivers mentioned

inadequate numbers as a challenge. All things being equal, the Koforidua Central Hospital being a secondary referral point is supposed to practise primary nursing care. Under the primary nursing care service, every patient has a designated nurse for planning the care and ensuring that the plan is implemented around the clock, seven days a week. However, this is not the case. Some LCs therefore complained that the limited number of nurses coupled with the high number of patients on admission is their motivation to provide care in the ward. Not only is the number of patients more than the nurses available but the quantum of work involved in caring for a single patient is enough to burn out the few nurses in the wards.

In relation to the problem of shortage of staff, the researcher sought to find out what should have been the actual nurse – patient ratio in the wards at KCH. The responses given by the nurses were all estimates. Literature on the universally accepted nurse-patient ratio varies. Even though some literature suggested four (4) patients to a nurse, the most determinant for patient - nurse ratio is the condition of health of the patient. This implies that seriously-ill patients will need more nurses to attend to them than those who are not seriously ill.

### **6.2c. Inadequate Logistics**

The third major institutional factor is inadequate supply of logistics to the wards. Not only are the logistics in short supply but some of the equipment are also obsolete. Some medicines are in short supply as a result lay caregivers have to go to town to purchase them for their relatives. Some laboratory tests and scans are also done outside the hospital because the hospital lacks such modern and sophisticated equipment. The issue of inadequate supply of logistics is discussed in detail in chapter eight.



### **6.3. Other Factors Influencing Caregivers**

As explained at the beginning of this chapter, factors influencing lay caregivers are multifaceted in nature. From the data gathered, the following were identified as other influencing factors. These are the severity of health condition, provision of information, fear of death of a relative value of human life and religious purposes.

The severity of the health condition of the patient was cited by 23 LCs. During the field work, apart from emergency cases, most of the patients were bed-ridden and unconscious. These patients need intensive care since almost, if not all aspects of their lives' needs are expected to be provided by someone else. The LCs therefore indicated that due to their patients' condition they could not leave them alone in the care of the nurses. Even though different descriptions were given about the health condition, the patient's inability to walk and or talk was the most mentioned ones. The severity of the ill-health condition of the patient, the researcher thinks has accounted for the large numbers of LCs in the hospital.

Due to the severity of the health condition which makes some patients unable to talk, the relatives are there to talk on their behalf. This is the main reason why most of them complained they should not be sacked from the room when doctors come on ward visitation. One of the participants however said due to the patient's inability to talk, she is not sacked from the room when doctors come on ward visit.

The participants intimated that since health workers run shift, there may be vital information about the patient which may be missing if those on duty before the incident happened did not document it. They therefore provide such vital information for further action to be taken on the patient. Perhaps, the long story of a 38 year old wife will help us understand this:

*“Sometimes, you would like to feed the patient but he will not eat because he has lost appetite. If the nurse is feeding and he says he will not eat, she will leave him and attend to another patient and may forget that your patient did not eat. But my patient is the only one I am caring for so if he does not eat at a particular time, I know and I can force him after some times to eat. Even if he ate and vomited, I know and if the doctor comes I can tell him he has vomited or something has happened to him at this time. The doctor may prescribe some medicine for him. For example, you (referring to the researcher) were a witness when I was asked to insert a medicine into his anus. As I was doing it, I saw a protruding object (kooko or hemorrhoid) and I drew the nurse’s attention to it. For all you know, the patient did not know that there was something like that in his anus. The nurse told me to inform the doctor so that he will be given some medicine. If I had left him in the hands of the nurses, they may be treating stomachache while a different sickness may kill the person. Also, the patient may be given a drug in the morning which may not come with any side effects but another may be given in the evening which may have some side effects. You, the caregiver can easily identify it and report to the doctor. For example, I have realised that his condition has not improved since we came two weeks ago. I discussed it with the doctors and they told me they have also seen it and this resulted in the change of the medication. I am not just with him. I am taking a critical look at things because it is not everything that the nurses will take notice off.”*

This statement is pregnant with multiple factors influencing this care caregiver. One of such factors is the provision of information on the patient’s response to treatment. Information is also provided on the emergence of a new ill health condition. The caregiver also provides information on the behavioural changes of the patient. Also, the caregiver wants to pay more attention to her relative because the nurses are overwhelmed with work and may not pay adequate attention to a single patient. She further influenced the change of medication for her husband when she reported she could not see any improvement in the condition of the patient. The statement *“I am not just with him. I am taking a critical look at things because it is not everything that the nurses will take notice off”* means so much that goes beyond ordinary caregiving.

Some caregivers fear their relatives may die if they are not around them. Death leaves pain in the lives of survivors. Sometimes, some people after their death reportedly haunt some people and reveal themselves to them complaining about the “bitter” death they have suffered especially if they are believed to have been killed by someone. Death also robs people of their precious loved ones and shatters the aspirations and dreams of many others, especially when their breadwinners die prematurely. The fear for the unknown coupled with human sympathy compelled some caregivers to be around.

The few wives interviewed supported their presence in the hospital from a religious perspective. This view is supported by Akintola (2010) when he investigated what motivated people to volunteer to provide care for AIDS patients in a faith-based organization in KwaZulu-Natal, South Africa. He found that a few of the volunteers were heeding a religious call, a call to care or show compassion to the sick and the needy. The caregivers in this study felt that since the marital vows they exchanged enjoined them to live together for better and for worse; and in sickness and in health they must respect that vow. Maame Mekaa furthered the argument by saying that the Bible says “two are better than one and if one falls, the other must lift him/her up” (Ecclesiastes 4 verses 9-10). Other LCs also felt their presence at the hospital would cause God to heal their patients. Assimeng (1995) describes Ghanaians as religious where every aspect of their lives is given a religious explanation. They therefore turn to God for deliverance and healing and Christianity for example promise aiding the individual to realise the fullest potential of his personality. The strong believe in the new forms of religion such as Christianity and Islamic, Assimeng (1995) reports, is described as “spiritual renaissance”.

The value lay caregivers place on the lives of their relatives is at the centre of lay caregivers’ involvement in institutional care provision. Irrespective of all other influencing factors, the value

of human life stands tall among the reasons given and as a result, LCs will sacrifice all the resources at their disposal to provide care for a sick relative. Not a single caregiver ended the interview without mentioning how valuable or important human life was. While expressing bitterness about her sibling's inability to assist her in caring for their mother and the burden of care, Oyokoa intimated:

*“...but human life is more precious. If I leave her here, there is nobody to care for her...the situation is such that, I cannot leave her alone. If I leave and come back to meet her dead, whom shall I ask or blame?”*

It may be concluded that “human life is more valuable than anything”, as a result, lay caregivers will sacrifice everything to provide care. Homans' (1974) value proposition of social exchange is at play here. Homans argues that the more valuable the result of an action is to a person, the more likely is the person to engage in such actions. Lay caregivers, therefore, see caring for their sick relatives, as very valuable.

This chapter has discussed reasons for engaging in care provision for in-patients at the hospital. The next chapter focuses on the experiences of the care recipients.

## **CHAPTER SEVEN**

### **PATIENTS' WARD EXPERIENCES**

#### **7.0. Introduction**

One of the objectives of this study was to examine patients' views on lay care giving in the hospital context. This chapter, therefore, gives an insight into the lived- experiences of patients in the hospital wards. It focuses on the demographic characteristics of the patient, care services available to the patients in the wards and patient satisfaction, the relationship that exists between health professionals and patients and challenges facing patients in the wards. Ujhely (1977) indicates that both nurses and patients come to the hospital ward with different expectations. While the patient sees the hospital as a place to get help or a solution to his or her ill-health and expects the health professionals to provide that need, the health professional is also influenced by his or her attitude towards human nature and personal and professional values. The HP is further influenced by his/her educational and experiential background, physical and emotional states and attitude toward his/her professional role. Senah (2002) has also indicated that both patients and physicians enter the medical setting with their own scripts aimed at advancing their respective interests. If the patient's expectation of the professional is not met, an alternative source of such help is sought. This has resulted in increasing and active participation of lay caregiving in the hospital context. The core business of this study therefore is to examine the values of lay caregiving in an institutional setting.

Five male and seven female patients participated in the study. Their ages range between 22 and 60 years. The patients spent between four days to one month in the hospital as at the time of the interviews. The majority of the patients were however in their second week as at the time the interviews were conducted. However, it must be noted that, some patients have lived with their

ill-health condition for over two years and were therefore regular patients in the wards. Various health conditions were reported. This included stomach upset, anaemic conditions, diabetes, stroke and post-operation conditions, among others.

### **7.1. Care Services and Patient Satisfaction**

Patients' satisfaction of care service is influenced greatly by the state of health and the expectations from the caregivers. Satisfaction is therefore subjective. What one may consider satisfying may not be considered so by another. Care services and patient satisfaction deal with the various forms of support patients received in the ward. It also discusses how patients assess or evaluate the support given them. From the study, all the patients except one received both professional and lay care. The only one who did not have any lay caregiver was, Asem, a thirty year old orange seller with a post-operation condition. Three other patients did not also have regular or permanent caregivers. One of such patients was Mununi who was cared for by a friend. Mununi's decision to come to the hospital was greatly influenced by friends and neighbours. The patient indicated that when she started feeling pains in the leg, she did not want to go to the hospital due to economic hardship. She started using herbal concoctions and sought the views of members of her social network on what she should do. When the situation deteriorated (leg became swollen), friends and neighbours impressed on her to seek professional medical care and also assisted her financially. This gives support to Chavunduka's (undated) assertion that in Africa, before many of the sick seek professional help, they make contact with others with whom they have close ties such as members of their family, friends, neighbours, workmates and employers. He indicated that these people influence the sick individual in the choice of therapy and usually continue to take care of the sick person throughout his illness

(Janzen, 1978/1982; Senah, 1981). However, in contemporary times, individuals take decisions on their own health status and do not necessarily contact members of their social networks when they have the resources to do so. This was the case of Ramatu, a 36-year old teacher who was suffering from stomach pains and body itching. It was also found that some patients came to the hospital after seeking medical assistance from other sources such as herbal clinics and spiritual healing centres or prayer camps. This plural medical behaviour has existed since time immemorial.

As mentioned in chapter five, the main form of care patients received from the health professional is medication while all other personal care needs were provided by the lay caregivers. Ideally, personal care needs of patients should have been provided by medical social workers but the latter do not exist in the health structure of Ghana. Although almony is an old profession, Ghana has social workers and not almoners. Five patients, however indicated that in the absence of their lay caregivers, health professionals provided them with some personal care needs by running errands such as buying food, call credit and turn them in bed. Additionally, Asem and Manu both of whom had no regular lay caregivers intimated that health professionals provided emotional needs in the form of comforting and encouraging them. It was observed during the data collection that some patients received care and support from other sources different from that of lay caregivers and the professionals. This form of support and care came not from individuals but from groups. This group could be Friendship Groups, Religious Groups, Non-Governmental Organisations (NGO), Professional Associations and the Social Welfare Services Department (SWSD). The main care need provided by this group was mostly financial. Mununi for example indicated her friends raised some funds to assist her because her husband was not financially sound and he was in Burkina Faso to seek greener pastures. As an orphan,

her siblings were also not in a position to help. Maame Korle and Maame Ohaw were also assisted by their church. What is significant here is that, in some cases, LCs are not just relatives but non-relatives who stand in the stead of relatives where the latter are not easily accessible.

It must be noted that the willingness of these patients to accept help or support from these caregivers reflects three of Parsons' sick role expectation that, the sick accepts the idea that he needs help; that he desires to get 'well'; and seeks technically competent help in getting well. However, in this study, the sick accept help from both technically competent, HPs and lay caregivers. This is due to the fact that the services of LCs complement that of the HPs.

#### **7.1a. Assessing Care: 'We are Managing'**

As indicated earlier, patients' assessment or evaluation of care is subjective based on the patient's expectation from the caregivers. Patients therefore expressed different opinions on the care provided by the health professionals and lay caregivers. Even though patients evaluate the care given them as generally good, one thing that was obvious from data gathered is that, patients had no choice than to do with the care provided them. It is probable that the patients would have described professional care differently if the interviews were done outside the hospital. Evaluating the care provided by health professionals as good, the study further investigated what constituted good care from the patients' perspective. The stories of Mr. Manu and Maame Ohaw may give an insight into this.

*"I am happy with the care provided by the nurses, doctors and the kitchen staff. Sometimes, I will be sleeping but by the time I wake up my food is on my table. Sometimes they will even wake me up to eat. It is not everybody who will have time like that. The work of the staff is to bring the food. It is not their responsibility to force you to eat but the staff here will try to let you eat the food."*



Similarly, Maame Ohaw added:

*“They help me a lot towards recovery. They pay prompt attention to me. The nurses and the doctors did their best by paying attention to me because the way my leg was deteriorating... If they had not paid prompt attention to me, my leg would have been amputated. God touched their hearts and they attended to me well”*

Even though it is the responsibility of the HPs to meet the needs of the patient, these patients saw the time and energy invested in them as good therefore concluded that they are well treated. Two patients were however indifferent about the quality of care provided by the health professionals. This was because their expectations from the health professionals were not met. One of them stated:

*“To some extent their services are okay but there are some who are not doing their work well. As human beings we are not perfect so definitely, some will do their best and the others will not do it hence we are managing”.*

“We are managing” here means she is not satisfied with the care given but there is no alternative hence she has to accept the situation as it was. To understand further what this patients meant when they assessed professional care given as good, bad or being indifferent, a question was asked on what patients expected from the HPs. To most of the patients, they expected the HPs to perform their assigned roles as professionally required with outmost commitment. They also expected them to assist patients with personal care needs in the absence of their LCs or even provide some form of emotional support to them. Mr. Djuma complained:

*“I feel when my wife is not around, they (HPs) should have engaged me in a conversation and that would have reduced my pains a bit. I also feel patients should have specific nurses to themselves if possible, one nurse to one patient.”*

The statement made by the patient above may sound conflicting but in a way, the patient may be right. This is due to the fact that provision of emotional needs is vital to the healing process. Even though it is not legally binding on the nurse to provide such emotional care professionally, the health worker is expected to counsel patients with special care needs like Mr. Djuma who was suffering from kidney problem. Mulemi (2010) reports that an encouragement given by a surgeon to a patient at the Cancer Ward in Kenya gave the patient hope and endurance in coping with the situation which finally ended in healing. Even though Mr. Djuma's request for one nurse to a patient is unattainable, his condition demanded much attention. It was not a surprise therefore when Mr. Djuma passed on five days after my encounter with him.

In the ward, I observed a nurse giving water to the patient in the absence of the lay caregiver. However, when the LC came, the nurse questioned her why she was not sitting by the patient. With this behaviour of the nurse, the nurse was by default formalising informality in the health care system. Maabra however suggested that the health professionals should have time for the patients and if they give the best treatment that they deserve they will recover quickly. One thing the researcher noticed was that patients presented health professionals in a more positive light than their lay caregivers did. The reason may be that the interview with the patients was conducted in the ward while lay caregivers' interviews were conducted outside the wards. The patient might therefore fear being victimised if found to report anything negative about the health professionals.

In evaluating or assessing the care provided by lay caregivers, the most common expression that came from the patient was that but for their lay caregivers, they did not know what would have happened to them as far as the provision of their personal care needs are concerned. The patients also never hesitated to ask for God's blessing for their LCs. They therefore saw the services

rendered them by their LCs as very valuable. Generally, patients were very grateful to their lay caregivers for the care provided them. One of them said:

*“I can only say God should bless her (a 14 year old daughter but not part of the study). From the pastor to all who have helped me, I say God bless them. But for the pastor who initiated this effort (gave her money to come to the hospital) and my daughter who is also caring for me, I would not know where I will be.”*

The care provided by the LCs also gave some patients the opportunity to assess or know the degree of commitment to the relationship that existed between them and their caregivers. To Akua, the saying that “a friend in need is a friend indeed” might have worked for her. She described her friend as very helpful and without whose help her stay at the hospital would have been described as hell. As Waliggo et al (2006:237) rightly put it, “although illness may disrupt a person’s life, it can also offer the opportunity to see life in a different way.” This statement was confirmed during the study. It was observed that some patients used their condition (hospitalisation) and the care they received from members of their social network to measure how others felt about or accepted them; the situation also afforded the sick to identify certain aspects of their lives they have never taken notice off. Some spouses used the care provided by their partners to measure their degree of commitment to the relationship. Maabra who was cared for by her husband intimated:

*“I am pleased with what my husband has done. I did not know he is so much concerned about me until I became sick. I will only say thank you to him.”*

Similarly, daughters could not hide their emotions and appreciation for what their mothers had done for them. In this regard, Kobbie, a 30-year-old man added to what the rest have said:

*“She has done well. She has helped me a lot. I don’t know what would have happened to me if my mother had not come to stay with me. I have derived a lot of benefits from my mother’s stay. I cannot mention them. The fact that she left her work to stay with me is great. I will just thank God. My mother has followed me to all the places I have been to.”*

To some, however, considering where they came from (distance) and the financial difficulties confronting most people these days, they were not worried about visitors. However, others were of a different view. To some of these patients, human beings are social beings and their desire to affiliate or have companionship is paramount. Buttressing the Maslowian (1954) thesis, these patients saw love and belonging needs as part of their basic needs. Human beings are gregarious animals and do not live in isolation but keep company with others. These expressions manifested during the field study. A patient expressed herself this way:

*“For human beings, if others do not get closer to you, you feel sad all the time but when they come you will feel happy. Someone may come to give you some money for koko or something else, so for me, their presence brings me joy”.*

From this, we can deduce that the patient see companionship and gift-giving as essential for human living. The absence of these will not augur well for the full realisation of life’s expectations. Thus, Asem who was without any lay caregiver stated:

*“I feel sad that I have a mother, the one who gave birth to me and when I became sick, she refused to care for me but I have given all to God (patient sobs). When I see other patients with visitors, I become very sad. If they (family members) had come, it would have given me comfort; even if I will not survive, they would have given me “awere kyekyre” (encouragement)”.*

*(The case of this patient is discussed in detail below).*

## **7.2. Developing Relationships in the Ward**

The hospital ward is one of the total institutions described in Goffman's (1961) *Asylum*. He defined "a total institution as a place of residence and work where a large number of like-situated individuals, cut out of the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life" (Goffman, 1961::xiii). In this regard, the hospital ward becomes a temporal residence for the patients while the staff sees it as their work place. Goffman (1961) indicates that in total institutions, both inmates and staff develop some level of attachment with each other. This has resulted in the ability of inmates to use their agency to influence the decision of staff towards them. He indicates that sometimes, inmates are able to influence staff to do certain things which will make life in the institution more comfortable for them. This implies that wherever two or more people come together for a common purpose, some level of attachment or bond develops between them. This form of attachment describes how each of the parties perceives the level of commitment that has developed between them. This attachment can also be seen in the level of the likeness each party develops toward the other. However, according to the social network theorist, the relationship that exists between members of a social network is influenced by the flow of resources. The coming together of patients from different backgrounds but confined in one area on one side and the professionals who they may not know before coming together in the ward on the other, provides the ground to study the relationship that develops between them. The development of a relationship between patients and the health professional staff was found in the hospital under study. This relationship could be described as good, lukewarm or bad. This study looks at the relationship that develops between the patients and the health professionals and the other patients in the wards.

In Goffman's (1961) *Asylum*, he indicates that inmates in total institutions such as hospitals develop solidarities and fraternities among them. He indicated “sometimes special solidarities extend throughout a physically closed region such as a ward or cottage whose inhabitants perceived they are being administered as a single unit and hence have a lively sense of a common fate” (Goffman, 1961: 59). As a result, they tend to engage in what he termed secondary adjustment where they learn to do things or behave in a way to get around with what is expected of them as inmates. Inmates also rely on each other for variety of assistance and emotional supports. Goffman further argued that the strong solidarity that develops between dyads and triads make them keep secrets from authority but whatever that is known to the majority of the inmates gets to the hearing of the authority.

Patients also develop some attachment among themselves in the ward. The fact that they are all sick and need assistance from someone makes them see themselves as one with a common plight. They therefore tend to be one another's keeper where the generally-weak patients are assisted by the stronger ones when the need arises. Patients seeing themselves as one hence giving assistance to one another was strongly expressed by Ramatu thus:

*“We have to live as a family. We support each other. If one person needs something, the one who is a bit stronger assists the person who is weak and that is how we live here”.*

Based on this assertion, she was asked whether she has received any help from another patient.

She answered in the affirmative and said:

*“Yes, I have received assistance from another patient. There was a time I could not get up and the other patient was a bit okay so, she assisted me to get down to urinate. I have also assisted some patients. This lady (pointing at a lady on a bed opposite her) is helpless so if it is time for the food to be served, I take her bowl and put it there and when the food is served, I bring it back, put it on the table and wake her up to eat”*

Patients helping one another was echoed by another when she indicated:

*“We help each other. If somebody cannot walk and another can walk the strong helps the weak. For example yesterday, a sister was brought here and the way she was behaving you could realise that she was weak. I stood up and went to look for her relatives but by the time they came she had expired, so we help each other”.*

Asem narrated how she assisted another patient. The role she played should have been played by the health professional or the patient’s relative. Her story is presented below:

*“A man came to the ward with his wife and when they came, I was a bit strong but the sister was weak. I told the husband to go and buy koko for her but when it was brought she refused taking it. I poured the koko into a plastic bottle and anytime she wanted water, I gave it to her and I did this several times after which I gave her a little water. When her husband went home, he did not come back early so I took care of her until her daughter came. When the man came, his wife told him what I had done for her and the husband was pleased with what I had done and promised to help me pay my bills when I am discharged”.*

Listening carefully to the narration of Asem, the researcher sought to find out how a patient could play such a caring role to a critically-ill patient in the ward. All things being equal, this care role should have been played by a health professional. The patient explained that when the woman was brought to the ward, the nurses were attending to another patient so she assisted her husband to provide the care needed.

Some patients also indicated that even though they did not know each other before coming to the ward, there existed a good relationship among them. As a result, they came together, to sing hymns and pray for their speedy recovery. Some added that they mostly sang songs from the Presbyterian hymn book to console themselves because most of them were all Presbyterians.

From the above explanations and examples, conclusion can be drawn that the need to help one

another is paramount in the ward, and friendship imperative. Also, as indicated by the social network theorists, the flow of resources and in this case, the various forms of help inmates received from one another influenced their relationship greatly. However, the level of cohesiveness may differ based on what brought them together and the level of familiarity that exists among them before coming together. We may therefore conclude that, patients who know each other before meeting in the ward develop stronger relationships than those who did not know each other before.

From the patients' perspective, the level of attachment between them and the health professionals was generally good. This, they said was influenced by the level of concern the health workers had shown them any time they came on visitation. To some, the way the nurses treated them made them to become friends in the ward. One of them stated:

*“Whenever they came, they called me Auntie Li, (Maame Korle) how are you? I also asked them if they have brought any fufu from the house. I normally ask those on afternoon shift and they will respond they brought some and we all laugh over it. So for me, all the nurses that have attended to me are all nice people”*

We can deduce from the statement above that there exists a cordial relationship between the patient and the health workers. However, this cordial relationship is sometimes influenced by the patient's relationship with a nurse before coming on admission. The statement therefore confirms an allegation made by one of the caregivers that in Ghanaian hospitals, the patients are better cared for by the nurses if they (patients) have some relationship with them or if the nurse is motivated with gifts by the patient's relatives. During the interview, Maame Korle made it known that one of the nurses was her church member. As a result, she introduced her to other nurses in the ward. The patient further added that the nurses visited her frequently even in the



absence of her church member nurse. In addition to this, even if the said nurse was not on duty, she came to visit her because their pastor had entrusted her in her care and any financial assistance from the church passed through that nurse. The nurse here even though professional also rendered services to the patient informally. Going by Talcott Parsons (1960) “Pattern Variables”, health professionals should ideally not be bothered with problems not related to their work. Also, with emphasis on universality, rules and regulations are supposed to be applied equally to all individuals irrespective of where they come from or who they are. As a result the relationship that is supposed to exist between health professionals and their patients is formal hence the behaviour of the nurse cited above could be described as contrary to Parsons’ pattern variable. However, Parsons notes that both types of pattern variables are needed even in modern society or organisations. The nurse’s behaviour of providing informal care services to the patient therefore cannot be considered a deviation.

This relationship notwithstanding, the level of relationship/attachment that develops between the patient and the health professionals is greatly influenced by power, status differences and the level of commitment of the health professional to duty. Even though the Patient’s Charter of Ghana gives power to the patient on the decisions affecting his/her health and well-being, lack of knowledge on such rights makes the patient feel powerless before the health professional. As a result, patients are compelled to behave well even in the face of annoying attitude of the HP for the fear of being victimised. The possession of medical knowledge by health professionals therefore makes patients feel unequal in the clinical encounter. This places the HPs and the patient in super-ordinate and sub-ordinate positions. As a result, patients with a low level of formal education especially, feel shy if not inferior before the professionals. This form of relationship is influenced by knowledge power rather than mutual respect and commitment.

The commitment of the professional to duty also greatly influences the kind of relationship that develops between the care provider and care recipient. Patients turn to be more attached to professionals who exhibit a high level of commitment to duty than those who do not. This is influenced by the fact that the sick person wants to be strong and anybody interested in helping that sick person to achieve his or her aim should be loved. It is, therefore, not surprising that, during the field study, some patients pointed at some nurses as those who have greatly impacted on their lives and prayed for God's blessing for them. However, personality traits cannot be left out of the factors influencing patient and nurse relationship. Max Weber, describes the charismatic authority as some whose personal qualities are loved by his followers. Thus, the charisma of some health workers influences the relationship that develops between them and the patients.

### **7.3. Challenges Facing Patients in the Wards**

In the previous discussions, some challenges of lay caregivers have been mentioned. Patients are also confronted with some challenges while on admission. This could be institutional or home factor. The major institutional challenge facing the patient is the neglect they experience in the ward. This has however been mentioned in the previous chapter. The major challenge worth discussing here is financial difficulties facing the patients. This is because financing health has been a problem for both individuals and governments over the years. The inability of some patients to pay for health services have resulted in the untimely deaths of many. Good health is tied to high productivity and the ability to pay for health services is essential in achieving good health. From the study, it was clear that, personal initiative to insure our health has not gone down well with the majority of the populace. Out of the 32 lay caregivers and 12 patients, only one patient had registered with a private health insurance scheme (Premier Health Insurance). It

is worth discussing financial challenges and measures that should be put in place to alleviate the financial burden on the health consumer.

The financial challenges some patients go through are similar to those lay caregivers go through. However, some patients were confronted with a more serious financial problem as a result; some were detained in the hospital even after they had officially been discharged from the ward. The stories of Asem, a thirty (30) year old orange seller and Maame Ohaw a sixty (60) year old unemployed woman may throw more light on the financial challenges facing some of these patients.

#### **Case 1: Asem**

This patient reported at the hospital with a post-operation problem for a review only to be admitted. According to her, she went through a surgical operation seven months earlier and was asked to be coming for review but due to financial challenges, she could not follow the routine check-up. She was at church when she experienced some unusual changes in the body and church members made a contribution of ten Ghana cedis (GH¢10) which she used as transport fare to the hospital. This patient was the only one who did not have any lay caregiver or even a visitor since she was admitted on the ward. She therefore lived on the benevolence of nurses, other lay caregivers and visitors to the ward. The patient was asked how she was able to survive without any caregiver and this is what she said:

*“The nurses and anybody who come to visit the other patients help me. They give me money which I use to buy food. Also when I take the koko served by the hospital in the morning, I manage it up to the afternoon and when lunch is brought, I keep it till evening which I normally eat before sleeping”.*

From this statement, it is clear that when needs are not available, people develop different strategies to cope with life. This patient deferred lunch for supper to be able to survive within the

hospital ward without a lay caregiver. This coping strategy however, has health implications. Food is essential for the proper utilisation of medication in the body. Forgoing a major meal implies taking medication on an empty stomach and the medical implications of this action are detrimental to the health of the patient.

When asked why nobody followed her to the hospital, she explained that when she went through the surgical operation, her mother was with her but did not follow her this time round. The patient further explained that, the mother was not happy with her because her mother borrowed money from people to pay the hospital bills for the operation and since she (patient) could not work, creditors were worrying her mother for their monies. As a result, the mother insulted her every day. According to the patient, her mother believed that, the condition which led to the surgical operation was spiritually inflicted upon her by the man who had a child with her. Due to the fact that the mother was not able to pay the first debts, she decided not to follow her to the hospital again to incur further debts.

The day of the interview was the third day after she was discharged from the hospital but could not go home because she could not pay her hospital bill of two hundred and fifty Ghana cedis (GH¢250.00). The researcher therefore sought to know about the supposed husband but the patient said she could not trace his whereabouts. She indicated that the supposed husband engaged in “galamsey” (surface mining) at Akwatia in the Eastern Region of Ghana and they were living together when she became sick. The man therefore asked her to go to her mother after they had tried some herbal medicines which did not work. The patient has two children less than 10 years from two different men. Due to the problem between her and the mother, the children were left in the care of a neighbour when she was coming to the hospital for a review. Now that the patient had been admitted and had spent more than two weeks at the hospital, the

fate of her children in the care of the neighbour was unknown. The patient was further interrogated on how she would manage to pay her bill and she answered outlining three strategies or avenues at her disposal. Firstly, she planned going to see the hospital Social Welfare Department (SWD) for assistance. Secondly, she would consult the churches around to plead for assistance if the hospital authority will permit her to go out. The third option she outlined was the help a man promised to give her. She indicated:

*“A man (the husband of the woman the patient assisted) came to visit his wife and asked me whether my relatives have come and I said no. He told me if God permits or if none of my relatives came, he will get some money to pay. I have been looking forward to seeing him since but he has not turned up. He called this morning and promised he will come and see me if he is able to raise some money”.*

Three days after the encounter with this patient, the researcher went back to the ward only to be told that she had gone home. However, the researcher did not find out how her bill was paid because the patient had no means of communication.

## **Case 2: Maame Ohaw**

As the name sounds, this patient's life was characterised by many challenges (Ohaw). This patient came to the ward with a swollen leg because she stepped on a bone. As a diabetic patient, her situation worsened and she was rushed to the hospital. She spent three weeks at the hospital. She could not pay the Three Hundred and Eighty Ghana Cedis (GH¢380 .00), hence her “detention”. The patient used to sell cookies but due to her ill-health, she had stopped. She had six children and were being cared for by her 14 year old JHS1 student, who was not always around to provide care because of her education. She added that, due to her poor health coupled with her inability to work, feeding is a problem but she is regularly assisted by the pastor of her church. However, her 14 year old daughter had to go round the neighbourhood sometimes to do

laundry for people in order to get some money for feeding. The patient narrated her ordeal in a sorrowful and disappointing mood:

*“Mo” (thanks). You have asked right. I even wanted to go to Social Welfare today but I cannot walk. My own children said they went for prayers somewhere and the pastor told them my frequent ill health is my own making because I am a witch. The pastor advised them to beat me up in the spirit until I die, otherwise, I will continue worrying them. I know in the name of God that, I am not a witch. It is diabetes that is worrying me. My children have deserted me and do not help me. They make me feel hungry all the time. Sometimes, some of the patients give me food to eat; I am suffering. Last time, I called my son and told him about my condition and pleaded I was starving but he did not mind me. Instead, he was rather laughing behind the phone (patient cries)...one of the nurses also called my daughter but she did not pick the call”.*

The researcher further interrogated the patient whether she reported the witchcraft accusation to the elders of the family and she answered in the affirmative. She however added that, the family elders did not say anything so she went to a prophet in Koforidua and the prophet invited one of her children and told her she was not a witch so they should change their behaviour and care for their mother but her daughter did not heed to the prophet’s advice. She (patient) went to four other prophets who all confirmed that she was not a witch. Yet her children were adamant.

If children have abandoned their own mother, what about other family members? The patient explained that, during her previous admission, a family member came to assist her. However, when that family member went to her (patient’s) room and saw the material things she (patient) had acquired, the family member called one of the patient’s daughters and told her if she did not come to care for the mother and she died, she (the family member) would not allow the girl to get a share of her mother’s possessions. The patient added she asked the family member whether she wanted her to die before sending such a message to the daughter. The family member got

angry and left her before she was discharged. Due to this experience, she felt inviting a family member was not necessary so she did not inform anybody. In the absence of her children and close blood relations, how can patients facing financial difficulties survive in the hospital wards?

*“Sometimes, I send my daughter to some churches to plead for money. For all this while I have been asking for alms. Sometimes, I ask my daughter to sell some of my clothes. This morning, I had wanted to go to social welfare so that they will assist me to go home but I cannot walk”.*

Before the patient was discharged, she disclosed that she was assisted financially by her church when she was asked to buy the apparatus for checking her sugar level. She said she was given three hundred Ghana cedis (GH¢300.00) but when she needed further funds for x’ray, she was not given any money. However, two of the church members came to visit her. The church also offered her 14-year-old daughter a scholarship to finish JHS. She was also assisted by one of the Orderlies in the ward to have the x-ray test. A later encounter with the patient revealed that, one of the church members came to pay the hospital bill to be refunded later.

The patient (Ohaw) lamented bitterly about how the financial challenges she was going through has caused her 14-year-old daughter to openly tell her that even though she initially rejected men’s sexual advances, she would now accept any proposal in order to get money to assist the patient and herself. From the researcher’s perspective, people would engage in some social vices when they are faced with challenges beyond their control. In the case of Adjoa (pseudonym), her elder siblings’ inability to take up the responsibility of caring for their mother pushed her to do what she would not have done under normal circumstances. Similarly, when health professionals are not able to take up their full responsibilities, the involvement of lay caregivers cannot be ruled out of the health delivery system. From child prostitution literature, Flowers (2001),

Mikhail (2002) and Muntarbhorn (1996) reveal that the act is sexual exploitation spearheaded by parents, teachers and other intermediaries but Adjoa's case is different. Her behaviour was at variant with Mikhail's (2002) finding that child prostitution is as a result of lack of freedom and the violation of a child's right to consent (Muntarbhorn, 1996). In this case, Adjoa had the choice to engage or not to engage in prostitution but she was compelled by circumstances to engage in the act. However, whatever form child prostitution may take, the bottom line is sexual exploitation and is for remuneration in kind, cash or for both.

Religion is supposed to be a unifier but currently in Ghana, some of our religious leaders are disintegrating families in the name of religious prophecies, visions and "directions". As Assimeng (1995:9-10) put it while comparing the traditional religion with the "new" religions of Christianity and Islamic "the original, mutually-tolerant notion of religious diversity, which had prevailed at the traditional level, came to be challenged by the aggressive, mutually-exclusive theological positions of these two new religions in their competition for souls." Even though Assimeng's statement focused on the forms of religion, these new forms of religion have brought about a lot of division and antagonism not only between their adherents and others but also among their adherents. This has resulted in the proliferation of churches with different and varying doctrines. While Islamic religion is known to have mainly the traditional moslems and Ahmadyia moslems, Christianity counts over thousand different groups and some preach against the doctrines of others resulting in disunity in Christendom. As far as division in the family is concerned, it is commonly known in Ghana that based on the Biblical quotation, Galatians 6: 10 "...let us do good to all men especially unto them who are of the household of faith" (KJV), a Jehovah's Witness adherent will do good to a member of his/her sect at the expense of a blood relation because the latter does not share the same faith with him/her. The witchcraft accusation



of the patient (Ohaw) resulting in her total neglect by her elderly children who are working and are supposed to care for their mother is one out of the numerous cases reported in the news day after day. In some cases, children pour acid on their mothers especially or inflict machete wounds on them because a prophet has told them their mothers are responsible for their challenges in life. This notwithstanding, religious affiliation is a source of help in times of needs as manifested in the lives of these two patients. Asem did not get much financial assistance from her church because she joined that church only during the Christmas festivities and also, the membership of the congregation is very small. It must be noted that, these patients are NHIS card holders but the scheme does not cover every aspect of medical treatment, hence their detention for non-payment of bills.

During one of the observational sessions in the ward, the mother of a patient who was detained for three days came with an amount of eight hundred and fifty Ghana cedis (GH¢850.00) out of the total bill of Eight Hundred and Seventy-Nine Ghana cedis (GH¢879. 00). While she went to the accounts office to pay, the nurse on duty received a telephone call from the hospital's Social Welfare Department. The message was to check whether the patient was still in the ward. The nurse reported that the patient's mother was around to pay the bills a few minutes before they called. In about ten minutes, the patient's mother came back in anger that the hospital bank where she was directed by the accounts officer to pay the money refused accepting the money because the amount was short of twenty-nine Ghana Cedis (GH¢29.00).

The nurse quickly called back the Social Welfare Department to report the incident to them. In no time, a gentleman and a lady from SWD came. However they could not offer any material help. After listening to the patient's mother, the officers realised they could not offer the needed help because the patient's mother had already gone through the "system" where every detail of

their financial obligation had been captured by the computer. The Officers explained that if the woman had seen them earlier, they would have written for a waiver so that the twenty-nine Ghana Cedis (GH¢29.00) would have been forgiven but once the “system” had captured the total bill, it must be paid. The only help they could give was to lead the woman to one of the offices to deposit the GH¢850.00 and later pay the rest. The researcher and the nurse on duty jokingly suggested the Officers should share the GH¢29.00 and pay. The Officers responded they do assist patients with their own money all the time but could not offer any help that day.

## **Conclusion**

So far, this chapter gives some insight into the lived experiences of patients in the ward. It highlighted the sources of supports they receive, the challenges that confronted them and the coping strategies they developed within the wards. Seeing themselves as one with a common plight, they developed cordial relationships among themselves which facilitates their coping strategies. In the following chapter, attention is given to the lay and the professional caregivers and how they play their roles in assisting the patients.

## CHAPTER EIGHT

### CROSSING THE PATH: THE COMPLEMENTARY ROLE OF THE LAY CAREGIVER

#### 8.0. Introduction

The interface between the health professional and the lay caregiver in the hospital can best be described as a “love-hate relationship”. This is because whereas at one point the health professional is happy about the presence of the lay caregiver as a helper, at another point, the presence of the latter is considered as a nuisance. The statements below and the discussions thereafter will explain better the “love-hate relationship” and the complementary role of the lay caregiver.

*“No one has asked me to stay here, but if it was not good for us to be here, the health professionals would have asked us to leave but they have not. If all that we have been doing since we came here is troubling them, they would have asked us to stop and go home for them to take care of the patients. No one has said whether our being here is good or bad and they have not sacked us so we are working with them.”(LC)*

*“The routine care that we give our patients is that, if it is a bedridden patient or unconscious patient, early in the morning, we give a bed bath. Depending on the patient’s condition, we give oral care after which we serve food before administering medication. However, if there are fewer nurses on the ward we direct the relatives to perform the early morning care that we should give the patient.”(HP)*

The above statements were made by a lay caregiver and health professional respectively. The statements highlighted on issues that are of great importance to this study. “We are working together” is the common issue identified in the statements of these caregivers. Health professionals and lay caregivers play a complementary role in care provision at the Koforidua Central Hospital. Quality professional health care therefore appears idealistic as care experience

is in three dilemmas. This is because in the first place, the professional care provider is limited in capacity but is expected to provide all the care needed. Secondly, the lay caregiver is not part of the chain of care provision and under normal circumstances is not central in the therapeutic processes. The third level of dilemma is that even though the lay caregiver does not form part of the chain, his/her services are needed to provide the needed care for patients on admission. As a result, he/she is invited from time to time by the professional to provide one form of care or the other.

This chapter therefore focuses on both the professional and lay caregivers with special attention paid to how health professionals and lay caregivers negotiate their roles within the care delivery system.

### **8.1. Routine Care Provided by the Health Professionals**

All health professionals interviewed mentioned the following as the routine care they provide for the patients. The care involves medication, personal care needs such of bathing, feeding and other hygiene care needs. It must be noted that, even though HPs administer medication to all patients, they did not hesitate to state that, personal care needs are provided based on the health condition of the patients. Patients with more serious health conditions, mostly unconscious and bedridden patients are assisted with personal care needs and not mobile patients. The statement made by one of the health professionals summed up the routine care provided for the seriously ill patient:

*“For the unconscious or bedridden patients, we normally give them a bed bath every morning, we feed them, change their diapers, change their bedsheets, change their clothes and we continue giving them the assurance and also serve them their due treatment”*

Medically, in addition to administering medications, HPs also check on the vital signs of these patients. The vital signs include checking temperature, pulse, sugar level and blood pressure among others.

According to one of the ward matrons, when patients are admitted on the ward and their condition becomes stable, they give them orientation on where they will get assistance when the need arises. They show them the washrooms and any other things the patient will need or use while on admission.

In addition to medication and personal care needs provided by the health professionals, they provide emotional care as well. They indicated that, they engage the patients in conversation through which they give them the assurance of hope and encouragement. To them, patients with chronic health conditions need counselling to cope with such health conditions hence they give them such emotional support.

## **8.2. Challenges Facing Health Professionals in the Wards**

Under-staffing and inadequate logistics were identified as the major challenges health professionals encountered in the discharge of their duties. In their annual performance review of 2016, one of the Medical Officers of the medical department in her presentation made this statement: “the major challenges facing the wards are shortage of staff especially nurses, inability of some patients to pay their bills on time, lack of some logistics like pulse oximeters, urine dipsticks, rapid diagnostics tests, (RDT, Oral quick) and infusion pump. Staff and official’s ward still lack certain logistics that befit the status of an official’s ward. There was lack of easily accessible computers on the wards which delayed daily ward rounds. Also there was no fridge for storing drugs and lack of personal protection equipment especially N95 face mask”

Since under-staffing was discussed in the previous chapters, the focus here is on inadequate logistics. It is difficult for health professionals to work without the basic logistics such as gloves, N95 face mask, thermometer and BP apparatus. However, some of these basic logistics were in short supply in the wards. Health professionals also complained about inadequate bed linen and as a result, some patients' relatives are asked to bring bedsheets. Some of the mattresses in the wards were also weak making sleeping on them a problem for the patients. Sometimes, batteries or dry cells to put in some of the apparatus to function were also lacking. What then should HPs do in the midst of these challenges? The common response was that, they improvised. In some cases, the nurse on duty had to use his or her own money to buy battery (dry cells) and gloves. However, these were not left for the use by other workers. One of them said:

*“Sometimes, we have battery problem with some of the machines like the SPO2 machine which we use to check the patients' pulse oximeter. As a result, you have to buy your own battery and keep it in your bag and use it when the need arises. This is due to the fact that before the administration serves you with the battery, it takes a very long time”.*

These challenges are not isolated as there is a historical precedence. In the quest to revamp Ghana's deteriorating economy in the early 1980s, the World Bank and the IMF prescribed certain measures. Some of such measures did not work well for the poor country and the health sector was one of the sectors that suffered greatly. The background to the deterioration in health care can therefore be traced to the implementation of the World Bank's Structural Adjustment Programme (SAP) and the Economic Recovery Programme (ERP) in the 1980s where subsidies on health care services were removed. Even though health care users were made to pay the full cost of care with the introduction of the “cash and carry” system, the health sector still faces challenges in meeting the needs of the sector (Eduah, 2014)

From the complaints the junior staff gave concerning inadequate logistics, the researcher sought the views of the senior nurses to know what they were doing about the problem. The views of the senior nurse were however different. Even though the senior nurses admitted that they experienced occasional shortages in the recent past due to the burning down of the Medical Warehouse in Tema, the misuse of the logistics by the some of the health professionals sometimes accounted greatly for the challenge. They indicated that some health professionals used the materials meant for the patients for personal gains. As a result, the Ward Matrons have to put some measures in place to ensure a judicious use of the logistics. For example, instead of putting all the boxes of gloves supplied to the ward at the disposal of the workers, some are put under lock and key to avoid misuse. One of the senior nurses explained that at the time of this study, the ward was supplied with adequate gloves, gauze and N95 face masks. It was also noted that, some medicines were in short supply in the hospital. As a result, some LCs were made to go outside the hospital environment to get them for their patients. The outstanding challenges in addition to the staff shortage were inadequate bed linen or bed sheets, inadequate supply of drugs and the use of obsolete equipment.

Inadequate supply of drugs and the use of obsolete equipment were also identified as a big problem to the HPs. Some drugs were in inadequate supply or were not in stocks. As a result, the nurses could not easily lay hands on them to administer to the patients. The nurses, therefore, depended on the family members to go outside the hospital to buy such drugs for their patients. Even though the “Cash and Carry” was said to have been abolished, the National Health Insurance Scheme does not cover all drugs. When drugs not covered by the scheme are prescribed, family members are called in to buy them. The inability of a lay caregiver to quickly buy the prescribed drug has implications on the patient. Even though the hospital is replacing

some of their aged equipment with modern ones, some of the new equipment cannot render certain services. Some of the laboratory tests, scans and x-rays are therefore done in town. Even bedridden patients who have been required to undergo some of these tests are carried to town for the tests. The hospital staff most often directs patients' caregivers to "Good Shepherd Scan Center", a private laboratory where they think the best result will be given the patient. The researcher on some occasions heard HPs directing caregivers to the said laboratory. One doctor said "I want the test done at Good Shepherd and no other place". When asked why they direct health consumers to do scans at the said centre, one of the medical officers indicated that the man in charge of the centre was the only radiologist in the whole of Koforidua, (this radiologist was a former employee of KCH) so they could rely on his reports for effective treatment.

### **8.3. Negotiating Roles and Space**

As McCann et al. (2008) indicated, the key emphasis in negotiation of care is discussion. This discussion does not only clarify the expectations and role delineation of each party, but also involves active role negotiation and decision making. From the data collected, it was found that health professionals did not engage lay caregivers in any discussions concerning what role to play in the care process and the degree to which they could be involved. The decision by lay caregivers to perform certain functions was greatly influenced by the patients' health condition. This has resulted in some conflicts between the lay caregivers and the health professionals when the latter found the former to be "going beyond limit". As Kirk (2001) reports, family members involvement in care provision is not subject to negotiation. This is due to the fact that, professionals find it difficult to accept the contemporary ideology of participatory care and also as a result of unequal power between the two (Allen, 2000; Trnobranski, 1994). McCann et al. (2008) also report that fear of increased infection rates, greater workloads, loss of power and



control and adherence to routine on the part of the health professional contributed to limitations being placed on parental involvement in care and as a result, the act is tolerated rather than encouraged by the health professionals.

### **8.3a. The Formality of Informality**

Even though it was observed and data also revealed HPs do not engage LCs in any mutual discussion regarding the extent to which they can go in the therapeutic process, data collected revealed different approaches adopted by both lay caregivers and health professionals in working together. The most common of such approaches is what Levy (1982) refers to as ‘staging’, and compromise is one of such approaches. Situational factors such as severity of patients’ condition and shortage of staff influenced the involvement of lay caregiving greatly. Due to this, the professionals adopted two approaches, formal and informal to get lay caregivers involved in care.

By the formal approach, the researcher refers to the situation where the lay caregivers are told to stay around to assist with care but this does not involve any official documentation or signing of any agreement. It does not also involve clarity of role expectation, delineation or negotiation. From the study, only seven (7) out of the 32 individual caregivers were reportedly formally informed. None of the thirteen (13) participants in the two FGDs was informed. Some of the HPs indicated they explained why there was the need for the lay caregivers to stay around. This explanation is however in a sentence “due to your patient’s condition, you have to stay around”. Other HPs confessed they did not give the LCs any explanation. Opanin Odame who brought an elder brother indicated:

*“When we came, we were asked not to leave him alone because they may need certain things that we have to buy and I am having the money so I have to stay around.”*

In response to how the HPs share their roles with the relatives that have been asked to stay around their patients, HPs indicated they taught the LCs what they were expected to do. One of them said:

*“We teach them how to cater for the patient. Last time for example, we taught the relatives of patients in the isolation room how to monitor the patient’s infusion so that when we are busy they can care for them. We provide the caregivers with gloves. I even taught one to study the level of oxygen on the patient and when it gets to a certain level she should come and inform me. I taught her how to close the line when the drip also gets finished. They are playing a complementary role so when they come, we teach them”.*

The views expressed above were supported by other HPs including the two ward matrons. However, majority of the LCs who were not asked to stay around explained why they decided to stay behind to provide care:

*“As I said earlier, the nurses only give medicine and it is left to you the relative to get closer to the patient and comfort him. Even though we have not been asked to stay around, sometimes they do ask “Who brought this patient here and the person may be asked to go and buy some medicines for the patient. If you are not close to the patient and there is the need to buy some drugs, they may leave the prescription with the patient meanwhile the drug is needed for his recovery”*

The above statement conflicts with what some of the health professionals have said concerning the care they provide the patients. As indicated by one of the HPs, they provide even personal care needs such as oral care and bed-bath for the patient. Whatever be the case, the need to provide all that the patient needs to feel comfortable and also to recover quickly influences some LCs to stay behind. The fear of neglect of the patient also influences the LCs greatly. This LC’s

concern was echoed by other caregivers who added that, due to the inability of their patient to care for themselves and the inability of the professional staff to render all the services needed, they stay around. A lay caregiver describes how she negotiated her way through:

*“At times, I would like to do something for my husband but they will be shouting ‘no! no! no!, don’t come!’ And you have to accept it. If you realise your patient’s condition is not bad you just have to accept what they tell you. Sometimes, you can say, ‘please! Auntie Nurse, I just want to do something “small” for the patient’ and they will allow you but when the doctors are coming on ward rounds, they will sack you. If you also see the doctors are around you have to leave the place. You have to behave in such a way that you would not implicate them and if you do that they will also be nice to you. You just have to respect their authority and humble yourself before them, for whatever they say you have to obey to be at peace with them”.*

The above statement indicates what Ward-Griffin (1998) described as disenchantment in negotiation relationship where the HPs behave contrary to the expectation of the LCs. This is because the LC is at a point invited to care for his or her patient but at the same time, while she is providing care, she is shouted at. However, the involvement of LCs is at variance with Max Weber’s bureaucracy. As Kreitner and Kinicki (2006) indicated, a bureaucracy should run like a well-oiled machine and its members should perform with precision of a polished military unit. However, Kreitner and Kinicki, (2006) admit that practical and ethical problems arise when bureaucratic characteristics become extreme or dysfunctional. On ethical grounds, quality health care must be provided for patients by HPs but inadequate number of HPs has resulted in the involvement of LCs.

From the data, the form of negotiation between health professionals and lay caregivers is seen in what Reck and Long (1985) identified as the Win-Win approach to negotiation. In this case, it is not only the negotiators (nurse and lay caregivers) that have their needs satisfied but the care

recipient (patients) also have their medical and personal care needs met. The nurses have their workload reduced while the LCs also have the opportunity to fulfill their moral obligation towards their sick loved ones. The whole issue of role negotiation between the HPs and LCs can best be represented diagrammatically as shown in figure 2.1 on page 48.

#### **8.4. The Value of Lay Caregiving: The Professional Perspective**

The value of lay caregivers in the therapeutic process in most Ghanaian public hospitals today cannot be overstressed in this study. Because the state has no clear policy on their involvement, their participation is considered as formalisation of informality. Irrespective of how we view their participation in health care delivery, lay caregivers play vital and complementary roles in the therapeutic process. All the nurses indicated that they found the LCs very useful as a result of the shortage of staff. They would therefore advocate for their formal involvement in the care delivery system. However, they did not hesitate to say that if the hospital is well-staffed, there would be no need for the LCs.

*“They are helping a lot because we are understaffed. If we have good staff - patient ratio, we can exclude them but as far as we are understaffed, we need them.”*

This statement shows lay caregivers are standing in the gap as a result of professional shortage whose genesis can be traced to the 1980s when most Ghanaian professionals left the country to seek greener pastures especially in the oil boomed Nigeria. According to Danielson et al (1993:16) the family influences recovery in so many ways: by the medical care it can afford, by the caregiving functions it serves and by the support it gives ill members. They argue that “the health-care provider who recognises the influence of the family will have a powerful ally in healing. However, if professionals ignore the family, the health-care system and the family will

be at cross purposes”. Danielson et al (1993) furthered their argument that health professionals need to encourage family coping by involving patients and their families in the diagnostic process and when families are not consulted or involved in the formation of treatment plans, plans formed may become impractical or impossible for the health care professional to implement because the family influences the decision concerning the appropriate care needs.

Even though nurses will advocate for the inclusion of lay caregivers in the therapeutic process, Medical Officers (MO) or doctors are of a different view. While acknowledging their current involvement in care, they will not advocate for their official involvement in care. One of them indicated:

*“I will not at all, advocate their involvement. One thing that worries us the most is when our patients are severely ill and are not supposed to be fed orally but by the time you realise they have fed them. As such the patient will aspirate especially our unconscious patients and for the medical ward that is our main problem with them because we lose most of those patients as a result of the actions of the lay caregivers who are always bringing food. As for the LCs we cannot take them out completely and we will always call on them as and when we need them so we normally take their contacts but to take them on 24/7 (full day a week) is completely out.”*

To another Medical Officer, the nurses do virtually everything including provision of personal care needs for the patients hence lay caregivers are not needed. This statement however is far from the truth. The differences in the views of nurses and medical officers on the inclusion of lay caregivers may be due to the contributions each of them makes toward the care for the sick in the ward. Whereas the MOs come on ward rounds to check on patients’ conditions of health, prescribe treatment and discharges those who have responded to treatment, the actual care for the

sick in the ward is done by the nurses. No wonder nurses will advocate for any action that will help alleviate their heavy care workload.

Lay caregivers however complained bitterly about how they are neglected by the HPs. Some stated that the HPs have refused to see them as partners in the care delivery system. As a result they are unconcerned about their welfare. LCs furthered their argument that no measures are put in place by the hospital authority to assist them. They have been neglected even though they play very important roles in complementing the efforts of the HPs. In response to this allegation levied against the HPs by the LCs, the HPs indicated measures are put in place to help the LCs. One of such is the hostel that is put up to house them. The second one is that they have designed a tag which the LCs use as an identification of acceptance into the wards. Once a caregiver wears the tag, he/she is not disturbed by the security men hence they get easy access to the wards. One of the nurses indicated that the tag was introduced in 2014. Towards the end of the study, the tag was not used by the patients' relative. When the researcher enquired from one of the ward matrons, she was informed that some the LCs were misusing the tag by giving it to other family members who are not recognised by the HPs as the caregiver for the patient to enter the ward anytime. Also some LCs were taking the tag home, hence, the use of it was suspended until further notice. Figure 8.1 is the tag and bears the inscription "PATIENT'S RELATIVE"



Figure 8.1: Lay Caregivers' Identification Tag

Furthermore, the health professionals indicated they allow those they have asked to stay with their patients to use the hospital facilities including sleeping in the wards with the patients. One of them explained that if all the beds are not occupied by the patients they allow the caregiver to sleep on the bed. However, if the beds are all occupied, the caregivers find alternative means of bedding. She added that in the absence of empty beds, LCs spread cloths or bedsheets on the hospital floor by their patient's bed which they allow. Thus, considerations for nosocomial infections are therefore relegated to the background. One of the nurses also suggested that since

the care provided by these caregivers complement the efforts of the professionals and also has economic value to government, one percent (1%) of the total bill of the patient must be borne by the hospital. They considered these as measures to assist lay caregivers.

Lay caregivers on the other hand have different views and expectations from the health professionals. They think more pragmatic measures rather than those just mentioned must be put in place to assist them. Their suggestions included but not limited to provision of free medical screening and treatment, free and comfortable accommodation, respect and commitment to duty by the health professionals.

Concerning free medical screening and treatment, the LCs indicated that since their involvement in care impacts negatively on their health, it will be most appropriate for the HPs to take their health issues into consideration to keep them healthy all the time. This will make them provide the needed help to the patient and also alleviate the HPs from their busy schedules and work overload. As discussed under the effects of care on the caregiver's health, most of them complained about different health conditions facing them due to their presence in the hospital. Discussants of the focused group indicated:

*“It will be proper for the health professionals to carry out routine medical care on us because there are some of us who could become sick even upon the sight of a sick person. If the doctors could attend to our health needs, we will be happy”.*

This view is shared by many other caregivers who added that since they are bitten by mosquitoes and also develop general bodily pains, medical treatment should be given them against these conditions. All the health professionals who participated in the study agreed with the LCs to undergo medical screening. One of the WMs even indicated that she assisted one caregiver to be attended to because she became sick during her stay in the ward. This was however not free.



What these HPs thought differently from the LCs is that, the medical screening and treatment should not be free. They added that, if they have the NHIS card, they could be assisted to access health care.

Hauser and Kramer (2004) report that even though health care systems rely on family members to provide care, sometimes the health professionals adopt an adversarial response to family members and view their involvement as problematic. Even though health professionals value the roles played by the lay caregivers, one of them indicated the LCs are sometimes “not co-operative”. Not co-operative as used here does not mean that the LCs did not want to work but rather, they forgot to follow strictly some of the directives given them. For example on the fourth day on the ward, the researcher observed a situation which HPs considered as “not co-operative” on the part of the caregiver. On this date, 21<sup>st</sup> January, 2016, just as the researcher was entering the ward, she saw one of the nurses blaming a caregiver for not following the prescription she was given. A medicine that was supposed to be given to the patient at night was wrongfully administered in the morning by the caregiver. There was therefore the need for reorientation as to how the medicines are to be administered. We should not be blind to the fact that this “not co-operative” behaviour will result in a more serious and complicated health condition. This notwithstanding, conclusions may be drawn that lay caregiving within professional care delivery system is more of a blessing than a bane.

The issue of accommodation was discussed in chapter five. Lay caregivers however expressed different views regarding respect and commitment to duty. The LCs suggested that the HPs should accord them some respect and see them as partners in care provisions rather than intruders. They should also not forget to be patient with them even if they do not follow their directives strictly. The LCs indicated that they are playing valuable roles which benefit both the

state and the health workers greatly. On the benefits to the state, they indicated that, instead of government employing people and paying them, they have stood in saving the state that cost. To the health professionals, they have relieved them of their busy work schedules. The LCs further argued that if the HPs were committed to duty irrespective of what challenges they may be facing, their presence in the hospital would not have been needed. To assist the caregivers therefore, the hospital staff must consider making life more comfortable for them by considering the suggestions they have given.

### **8.5. Lay Caregivers and Health Professionals: the Nexus**

Lay caregivers expressed different views on how they perceived the kind of relationship that exist between them and the health professionals. Relationships could be described as good or bad. Whereas some LCs described their relationship as good, others were indifferent. Another category of caregivers saw their relationship with the professionals as one based on power.

Most of the lay caregivers described their relationship with the health professionals as generally good. This is due to the fact that they did not have any open confrontation with the HPs. The LCs indicated that, unlike other health centres where HPs show open hostility towards patients' caregivers, this was absent at KCH. The doctors and nurses were all considered to be generally friendly to the admiration of the caregivers. Despite the challenges faced by caregivers as noted earlier, they intimated that they work in an atmosphere of peace as far as their relationship with the health professionals is concerned. However, this good relationship did not come by itself. It was consciously built through caregivers' strict adherence to the instructions given them by the HPs. Another factor that influenced this good relationship was the caregiver's own effort to

maintain peace between the two parties as some indicated that they tried to ignore what will not go down well with them due to their patient's welfare.

Other lay caregivers could not describe exactly what they felt about their relationship with the health professionals. They could not say they had a good or bad relationship with HPs. This notwithstanding, some caregivers believe that, the relationship between them and the health professionals was that of power. The health professional gains his/her power from his /her field of study as a professional. Also, the fact that he/she determines the cause of action in the position of care provider confers so much power on him or her. One of the caregivers intimated:

*All of them are more learned than me. I ended my education at form four but all of them have higher education. Now, they use certain terms when talking. They already know from head to toe. "Obi nkyere akora or akola Nyame" (No one teaches the child who God is) or does someone teach the child about God?"*

The expression of this caregiver re-enforces the super and sub-ordinate relationship between HPs and LCs. Even though the Patient's Charter of Ghana has given patients' rights and authority over decisions concerning their health, this caregiver is powerless due to lack of knowledge concerning medical treatment. Hence, she sees the health professional to be very knowledgeable and cannot be directed as to what to do. The professional knows it all. This limits or incapacitates most caregivers and as a result, they cannot even approach the HPs when they feel something is not going on well with their patients.

Apart from having all hands on deck as one of the multidisciplinary approaches to care delivery, another important thing to be considered is the plural medical system. This approach calls for the use of multiple solutions for tackling ill-health condition. By this, a sick person may combine Western mode of healing with traditional and or faith-based remedies to tackle a single health

problem. This is due to the fact that in the African context and for that matter Ghana, illness may have multiple causation. To Suleiman (2007) “the African conception of health assumes a holistic perception, which asserts that the state of health includes political, social, economic and “religious” well-being of the individuals and communities”. Thus, all possible means of assisting the sick to recover must be seriously pursued. Therefore, in an attempt to provide “proper” or quality health care, all aspects of health as conceived by the African and for that matter the Ghanaian, must be attended to.

In this chapter, discussions have focused on the questions addressing lay caregivers’ involvement in professional care. The relationship that exists between these caregivers and how they negotiate their roles in the therapeutic process were discussed. The next chapter provides a summary on the topic investigated. Recommendations are also made for policy consideration and for future research.

## CHAPTER NINE

### SUMMARY AND RECOMMENDATIONS

#### 9. 0. Introduction

The introduction of hospitals in the Gold Coast has brought about changes in the health sector over the years. Hospitals which were named death-houses by Cockerham (2007) have now become homes for many seeking good health as a result of advancement in technology and improvement in medical findings. Irrespective of the achievements gained in the health sector resulting in the provision of better care system, the sector is still confronted with certain basic challenges including inadequate health professionals and logistics which have resulted in the phenomenon under study. This study, therefore, highlights the current challenges confronting Ghana's health care system and how both the health care providers and consumers have developed strategies to cope with the system.

The major findings are based on the four specific objectives of the study which are: to determine the socio-cultural factors that influence lay caregivers to provide care; investigate institutional factors that facilitate or hinder lay care giving, examine patients' and medical staffs' views on lay care giving in the hospital context and find out how lay caregivers and health professionals negotiate their roles within the hospital settings. In furtherance of these objectives, the study also sought to examine the nature and dynamics of lay care giving in an institutional setting. Since the ultimate aim of the study was to inform policies on general care for the hospitalised and to contribute to the literature on institutional care in a non-Western context such as Ghana, recommendations are made with reference to these objectives and other findings.

## **9.1. Major Findings**

Based on the objectives of the study and other findings which came up during the field work, findings are classified into:

- (i) Factors influencing lay caregivers to provide care in institutional settings.
- (ii) The experiences of patients in the wards and their views on the value of lay caregiving;
- (iii) The challenges confronting health personnel and their views on the value of lay caregiving.
- (iv) How health professionals and lay caregivers negotiate their roles.
- (v) The general background of lay caregivers and caregiving environment.

### **9.1a. Factors Influencing Lay Caregiving**

Factors influencing lay caregivers are grouped into three. These are socio-cultural, institutional and other factors which could be medical or personal. Socio-cultural factors influencing care include: caring as a moral obligation, caring for reciprocity and caring as a tradition. Even though these three factors may sound the same as they are greatly influenced by culture, there are slight differences between them.

- Caring as a moral obligation is greatly influenced by the relationship that exists between the patient and the caregivers. The age of the patient (often 60 years and above) and his or her condition of health also makes it a moral obligation for the caregivers to provide care. It was further identified that caregiving is influenced by order of birth, sex, proximity to patient and financial standing of the caregivers. However, in the traditional rural

Ghanaian environment, the head of the family plays a very important role in the care of his sick family members. This may not be the case with the urban dwellers.

- As far as reciprocity and caring as tradition is concerned, caregivers feel that it is good to reciprocate the good that the patient has done to them. Caregivers believe traditionally, the sick must be cared for by family members and failure to do so will result in public mockery. Societal expectations and perceptions therefore influence these caregivers greatly.
- Both lay caregivers and patients come to the hospital with certain expectations from the health care providers. The inability of the latter to meet the expectations of the former account for lay caregiving in hospitals. The institutional factors influencing lay caregivers are those that are present or absent or are imagined to be present or absent from the hospital and that negatively interfere with the provision of quality care for the sick. Three institutional factors identified are shortage of staff, negative attitude of some health professionals and the hospital's inability to provide three meals daily for the patients.
- Other factors influencing care include the severity of ill-health, provision of information on the condition of the patient and fear of death of a relative. Some patients in the ward were seriously ill. While some were bed ridden, others were unconscious. Caregivers, therefore, provide information on the condition of health when doctors come on ward rounds. Some caregivers also entertain fear that their relatives will die in their absence. Spouses supported their patients in the hospital from a religious perspective. Maame Mekaa for example intimated that since the marital vows they exchanged enjoin them to stay together "for better and for worse and in sickness and in health" they must respect that vow. She furthered her argument that the Bible says "two are better than one and if

one falls, the other must lift him/her up” (Ecclesiastes 4 verses 9-10). Others also feel their presence at the hospital will cause God to heal their patients.

### **9.1b. Patients’ Views on Lay Caregiving**

Data shows patients reported at the hospital with various health conditions such as stomach upset, anaemia, diabetes, stroke, post-operation conditions and general health problems. Before coming to the hospital, patients sought medical attention from other sources such as traditional healers and spiritual healing centres or prayer camps. The majority of the patients were in their second week as at the time of the interviews. Data revealed that, all patients except one received both professional and lay care. The only one who did not have any lay caregiver provided her personal care needs because she was not bedridden. It was identified that apart from health professionals and lay caregivers, some patients received financial assistance from charitable organisations and the Social Welfare Services Department (SWSD) of the hospital.

- Patients describe lay caregiving as valuable. The involvement of lay caregivers gives the patients the opportunity to assess the degree of primordial ties that exist between them and their caregivers. Some patients suggested lay caregivers should be given more room to operate within the hospital as they provide much emotional support.
- Most of the patients described the relationship that exists between them and the HPs as good. This is however influenced by the level of the HP’s commitment to duty and his or her expertise. Inter patient relationship develops leading to receiving mutual assistance. Patients who are a bit strong tend to help the generally weak in the absence of their caregivers.
- The major challenges confronting patients are negligence of duty by some HPs and finance.



### **9.1c. Health Personnel's Views on Lay Caregiving**

Health professionals provide basic care for the patients. The cares include medication and personal care needs such as bathing and feeding. This is however not done by the health personnel alone, they are assisted by lay caregivers. Counselling services are also given to those patients with chronic health conditions.

In the course of providing these care needs, the HPs are confronted with some challenges. The major challenges are inadequate staff (nurse-patient ratio) and logistics. Health professionals complained about inadequate supply of basic logistics such as gloves, face masks, thermometer and BP apparatus. Additionally, HPs also complained about inadequate bed linen and as a result, some patients' relatives bring their own bedsheets. Sometimes, batteries or dry cells to put in some of the apparatus to function are also lacking. Inadequate supply of drugs and the use of obsolete equipment are not left out of the list of challenges confronting health personnel. Some drugs are bought and some laboratory examinations are done outside the hospital.

- Expressing their views on the value of lay caregivers, HPs indicated they found the LCs very useful as a result of the shortage of staff. They would therefore advocate for their formal involvement in the care delivery system. However, they never hesitated to say that if the hospital is well staffed, there will be no need to include the LCs.
- To show how valuable the lay caregivers are in the care delivery system, the HPs indicated that the hospital has put up a hostel to accommodate the LCs. In addition to the accommodation provided, they have designed a tag bearing the inscription "PATIENT'S RELATIVE". This gives the LC an identity and therefore easy access to the ward.
- In some cases, the HPs indicated they provide medical care to LCs who complained of poor health and have NHIS cards. This notwithstanding, the lay caregivers feel more

pragmatic measures such as provision of free medical screening and treatment, free and comfortable accommodation be put in place to assist them. LCs also expected respect and commitment to duty from the HPs. The lay caregivers however indicated that there exist a good relationship between them and the health professionals.

#### **9.1d. Negotiating Roles and Space**

Since there is no formal contract between health professionals and lay caregivers, the latter's involvement is tolerated due to situational factors: the severity of patients' condition and shortage of staff. The lay caregivers are at times permitted by the health professionals to assist with the care while at other times, LCs get involved in care provision without permission from the health professionals. The involvement of lay caregivers is therefore a mutually accepted compromise based on win-win approach.

#### **9.1e. General Background of Lay Caregivers and Caregiving Environment**

Data from the study reveal that:

- There are more female than male caregivers and caregiving is no longer the preserve of the elderly as children between 13-17 years were also found within the caregiving environment. The involvement of children of school going age in care in an institutional setting is of great concern because it has implications on their education and health.
- Most of the caregivers were self-employed and this made them easily available to provide care in the hospital. The reason is that, they do not need to take permission from employers before leaving their work to provide care.
- The educational levels of these caregivers were rather low, majority were basic school graduates. This low educational background placed them in the informal sector of the economy where most of them were masters and mistresses of their own businesses.

- It was also found that most of the caregivers had close blood relations with the patients they are caring for. Family members' responsibility towards each other is still crucial even in the face of social change.
- From the study, caregivers may be broadly classified on the residential pattern they adopted and on the degree of involvement in the provision of care. On the residential pattern adopted by these caregivers, two categories of caregivers are identified. These are resident caregivers and non-resident caregivers.
  - Resident caregivers were those who due to the long distances between their homes and the hospital and the severity of the condition of health of their patients decided to move in or live around the hospital environment.
  - The non-resident caregivers on the other hand are those who due to the close proximity of the hospital to their homes and non-severity of the health condition of their patients, decided to stay at home but come to the hospital regularly to care for their patients. It must be noted that caregivers whose homes are close to the hospital but patient's condition is severe live in the hospital.
- The second major class of caregivers which is based on the degree of involvement in care provision is put in three groups namely: (1) permanent or regular caregivers (2) non-permanent or irregular caregivers and (3) shift caregivers.
  - The regular or permanent caregivers were those who were directly involved in the day-to-day care of the patient on admission and were always found in the hospital providing one form of care or the other to the patient.
  - The non-permanent or irregular caregivers are those who are not directly involved in the day to day care of the patient but however provide certain services to assist the sick.

- Shift caregivers actually take part in the provision of personal care needs of the patient but for their engagement in equally important activities cannot stay in the hospital all the time. The main difference between irregular or non-permanent and shift caregivers is that while the former does not necessarily get involved in the day-to-day care of the patient, the latter does.
- It was also discovered that most caregivers have a bare knowledge on the condition of health of their patients. They could not tell medically the diagnosis of their patients. This may be due to the super- and sub-ordinate relationship that exists between the health professional and the caregivers. Also, the inability of the caregivers to claim their health rights as enshrined in the Patient's Charter of Ghana, account for this.
- The types of care provided are grouped into emotional, financial, physical and spiritual.
- Most caregivers will not opt for a paid caregiver for their patients on the grounds that the paid carer may not take proper care of the sick and also on moral obligation towards the sick.
- The most common challenges facing caregivers are both institutional and home. The institutional challenges are inadequate accommodation, lack of access to information, poor environmental hygiene and inhuman treatment. The main home factor is inadequate finance.

## **9.2. Recommendations for Policy Implementation**

Based on the various findings, the following recommendations are made:

- As a short term measure, the Ministry of Health in conjunction with the Ghana Health Service should formulate policies that create room for lay caregivers' involvement in

provision of care for in-patients at the hospital. This may be included in a revised Patients' Charter.

- There is the need for government to recruit more health personnel to reduce the workload on the few working in the wards. Work overload which leads to fatigue has resulted in negligence of duty by some health professionals and fostered lay involvement in the provision of health care to in-patients.
- Logistics such as modern BP apparatus, sophisticated laboratory and x-ray equipment and adequate drugs should be supplied to the hospitals to make professional work very effective. The Ministry of Health must undertake a needs assessment of the KCH so as to provide it with equipment and logistics necessary for effective health care delivery. In the same vein, the KCH must put in effective measures to ensure effective and economic use of available resources.
- All things being equal, the Koforidua Central Hospital authorities should consider assigning a specific number of patients, preferably four (4) to a team of health professionals at a time to enable such personnel to be responsible for monitoring of the therapeutic process of such patients. This approach will reduce the shortfall in the current general practice where nurses on duty are responsible for monitoring the care process of all patients on the ward irrespective of their numbers. Even with the current staff strength, assigning patients to nurses will make the latter more responsible and accountable.
- As patients need food for their medication (and not all patients on the ward have lay caregivers), food should be served on time and the number of meals needed per day should be provided for the patients even at a cost to the patients.

- A practice where unless payment for a particular service is done (Cash and Carry) before such a service is rendered to the patients should be discouraged to reduce the mortality rate in the wards since some patients die as a result of their family members' inability to pay promptly for certain services at the time that the patient seriously needs them.
- More washrooms should be provided in the wards and the place kept neat all the time than the two that exist currently which are used by over forty patients and sometimes with their caregivers.

### **8.3. Recommendation for Future Research**

The following research area should be considered by other researchers:

A nationwide study should be undertaken by MOH to ascertain the role of lay caregivers and the views of health professionals on the role of lay caregivers.

### **8.4. Contribution to Knowledge**

Even though several works have been carried out on lay caregivers' involvement in the provision of care at the hospital, most of them are foreign-based and as such available literature lack local experience. Furthermore, most of the empirical studies have been done in tertiary health institutions. Care for the terminally ill, chronic and degenerative diseases, elderly and children have also been the attention for most studies.

This study has made a modest contribution to knowledge in the field of Sociology of Health and hospital ethnography focusing on enculturation of the hospital as an alien institution in a non-Western cultural milieu. The study therefore highlights the dilemmas and friction that exist between indigenous and foreign norms with respect to in-patient care.

By studying the interface between the health professionals and lay caregivers in an institutional setting, the study also articulates the dynamics that characterise the relationship between the professionals and non-professionals in a quasi-bureaucratic setting.

### **8.5. General Conclusion**

From the foregoing discussions, it may be concluded that in Ghana, lay caregivers' involvement in professional health care delivery is rooted in social exchange. This exchange is influenced by the culture of the people and the perceived reward to be received at the end of such actions. Societal norms such as rules of reciprocity and moral obligations influence lay caregivers greatly.

It is also clear that, currently, quality health care cannot be achieved without the active involvement of lay caregivers. Therefore, strict adherence to bureaucratic procedures and professionalism cannot produce the best health outcomes in Ghanaian public hospital. As far as the provision of quality health care is concerned, situational factors must be taken into serious consideration and the necessary amendments made to create room for the involvement of all stakeholders in the health sector to operate. The social context of care or the cultural values of the people must also be given attention. As Akrong (2009: 111) rightly puts it:

*“In the age of globalization, what is needed is not universal standardization of health and care but rather the contribution of the various local health systems of care to the already existing system, in order to enrich the range of services that can be accessed from different health care systems. In the final analysis health can justifiably be viewed as a cultural system and the definition of illness, its diagnosis and treatment brings together interconnected social institutions that make up the health system of a local culture.”*

From the above statement, it is clear that in contemporary times, health care delivery should not be the sole responsibility of only the health professionals but rather it should be the collective responsibility of both the professionals and non-professionals. This is due to the fact that health care has its professional and non-professional aspects. This is more so in the context where health personnel are in short supply.



## REFERENCES

- Abraham, C., & Shanley, E. (1992). *Social Psychology for Nursing, Understanding interaction in Health Care*. London: Edward Arnold Fourth Impression.
- Addae, S. (1997). *The Evolution Of Modern Medicine in a Developing Country: Ghana 1880-1960*. Durham: Durham Academic Press Ltd.
- Ae-Ngibise, K. A., Doku, V. C. K., Asante, K. P., & Owusu-Agyei, S. (2015). The experience of caregivers of people living with serious mental disorders: a study from rural Ghana. *Global Health Action*, 8(1), 26957.
- Airhihenbuwa, C. O., & Webster, J. D. (2004). Culture and African contexts of HIV/AIDS prevention, care and support: original article. *SAHARA: Journal of Social Aspects of HIV/AIDS Research Alliance*, 1(1), 4-13.
- Akintola, O. (2010). What motivates people to volunteer? The case of volunteer AIDS caregivers in faith-based organizations in KwaZulu-Natal, South Africa. *Health policy and planning*, czq019.
- Akrong, A. (2009). Spiritual healing and Care in African Indigenous Churches. In C. Oppong, P. Antwi & K. Waerness (Eds.), *Care of the Seriously Sick and Dying. Perspectives from Ghana* (pp. 92-113). Noway: Unifob Global.
- Alatinga, K. A., & Williams, J. J. (2014). Development policy planning in Ghana: The case of health care provision. *European Scientific Journal*, 10(33).
- Allen, D. (2000). Negotiating the role of expert carers on an adult hospital ward. *Sociology of Health & Illness*, 22(2), 149-171.

- Allen, S. M., & Ciambrone, D. (2003). Community Care for People With Disability: Blurring Boundaries Between Formal and Informal Caregivers. *Qualitative Health Research*, 13(2), 207-226.
- Altimier, L. (2015). Compassionate Family Care Framework: A New Collaborative Compassionate Care Model for NICU Families and Caregivers. *Newborn and Infant Nursing Reviews*, 15(1), 33-41.
- Andrén, S., & Elmståhl, S. (2007). Relationships between income, subjective health and caregiver burden in caregivers of people with dementia in group living care: A cross-sectional community-based study. *International Journal of Nursing Studies*, 44(3), 435-446.
- Anyinam, C. A. (1989). The social costs of the International Monetary Fund's adjustment programs for poverty: the case of health care development in Ghana. *International Journal of Health Services*, 19(3), 531-547.
- Appelrouth, S., & Edles, L. D. (2008). *Classical and Contemporary Sociological Theory*. Los Angeles: Pine Forge Press.
- Arhinful, D. (2003). The solidarity of self-interest: social and cultural feasibility of rural health insurance in Ghana. African Study Centre, Leiden.
- Assimeng, J. M. (1995). *Salvation, Social Crisis and the Human Condition*. Accra, Ghana: Ghana University Press.
- Atobrah, D. (2009). *Caring for the Chronically Sick within Ga Families; A Study of Modern Innovations and Traditional Practices*. Unpublished PHD thesis, University of Ghana, Legon.

- Aziato, L., & Adejumo, O. (2014). Psychosocial factors influencing Ghanaian family caregivers in the post-operative care of their hospitalised patients. *Africa Journal of Nursing and Midwifery*, 16(2), 112-124.
- Badasu, D. (2009). Care for the Seriously Sick Children at Korle Bu Teaching Hospital. In C. Oppong, P. Antwi & K. Waerness (Eds.), *Care of the Seriously Sick and Dying, Perspectives from Ghana* (pp. 150-187). Norway: Unifob Global.
- Baxter, P., & Jack, S. (2008). Qualitative case study methodology: Study design and implementation for novice researchers. *The qualitative report*, 13(4), 544-559.
- Bee, P. E., Barnes, P., & Luker, K. A. (2009). A systematic review of informal caregivers' needs in providing home-based end-of-life care to people with cancer. *Journal of clinical Nursing*, 18(10), 1379-1393.
- Blum, K., & Sherman, D. W. (2010). Understanding the Experience of Caregivers: A Focus on Transitions. *Seminars in Oncology Nursing*, 26(4), 243-258.
- Bragstad, L. K., Kirkevold, M., Hofoss, D., & Foss, C. (2014). Informal caregivers' participation when older adults in Norway are discharged from the hospital. *Health and Social Care in the Community*, 22(2), 155-168.
- Chavunduka, G. L. (undated). Traditional African Perception of Illness. University of zimbabwe Publications
- Claymana, M. L., Roterb, D., Wissowc, L. S., & Bandeen-Roched, K. (2005). Autonomy-related behaviors of patient companions and their effect on decision-making activity in geriatric primary care visits. *Social Science & Medicine*, 60, 1583–1591.
- Cockerham, W. C. (2007). *Medical Sociology* ( 10th Ed ed.). New Jersey 07458: Pearson Education, Inc., Upper Saddle River, .

- Coser, L. A. (2010). *Masters of Sociological Thought, Ideas in Historical and Social Context* (2nd ed.). Orlando, Florida: Harcourt Brace Jevanovich, Inc.
- Creswell, J. W. (2008). *Research Desisign: Qualitative, Quantitative And Mixed Method Approaches* (3rd ed.). New Delhi: Sage Publication, .
- Cropanzano, R., & Mitchell, M. S. (2005). Social exchange theory: An interdisciplinary review. *Journal of management*, 31(6), 874-900.
- Daniels, K., Clarke, M., & Ringsberg, K. C. (2012). Developing lay health worker policy in South Africa: a qualitative study. *Health Research Policy and Systems*, 10(1), 8.
- Danielson carol B, Brenda, H.-B., & Patricia, W.-F. (1993). *Families, health & illness: perspectives on coping and interventions* USA: Mosby-Year Book Inc.
- Darbyshire, P. (1994). *Living with a sick child in hospital: the experiences of parents and nurses*: Chapman & Hall.
- del-Pino-Casado, R., Frías-Osuna, A., & Palomino-Moral, P. A. (2011). Subjective burden and cultural motives for caregiving in informal caregivers of older people. *Journal Of Nursing Scholarship*: 43(3), 282-291.
- Denton, J. A. (1978). *Medical Sociology*. Boston: Houghton Mifflin.
- Doherty, W. J., & Mendenhall, T. J. (2006). Citizen health care: A model for engaging patients, families, and communities as coproducers of health. *Families, Systems, & Health*, 24(3), 251.
- Duncan, M. T., & Morgan, D. L. (1994). Sharing the caring: Family caregivers' views of their relationships with nursing home staff. *The Gerontologist*, 34(2), 235-244.
- Durkheim, E. (1951). *Suicide: a Stuidy in Sociology*. New York, The Free Press

- Eduah, G. (2014). *The Impact of the World Bank's SAP and PRSP on Ghana: Neoliberal and Civil Society Participation Perspectives*. (Master of Arts), University of Ottawa.
- Emanuel, R. H., Emanuel, G. A., Reitschuler, E. B., Lee, A. J., Kikule, E., Merriman, A., & Emanuel, L. L. (2008). Challenges faced by informal caregivers of hospice patients in Uganda. *Journal of Palliative Medicine*, 11(5), 746-753.
- Emerson, R. M. (1976). Social exchange theory. *Annual review of sociology*, 2(1), 335-362.
- Faria, S. H., & Schall, M. B. (1997). Assisting lay family caregivers: Promoting independence as a method of coping. *Home Care Provider*, 2(2), 65-68.
- Feeney, B. C., & Collins, N. L. (2003). Motivations for caregiving in adult intimate relationships: Influences on caregiving behavior and relationship functioning. *Personality and Social Psychology Bulletin*, 29(8), 950-968.
- Flowers, R. B. (2001). The sex trade industry's worldwide exploitation of children. *The Annals of the American Academy of Political and Social Science*, 575(1), 147-157.
- Foa, E. B., & Foa, U. G. (1980). Resource theory *Social exchange* (pp. 77-94): Springer.
- Franzoi, S. (2000). *Social Psychology* (2nd ed.): McGraw-Hill College.
- Freidson, E. (1972). *Profession of Medicine*. New York: Dodd Mead & Company
- Frohlich, D. O. (2014). The social support model for people with chronic health conditions: A proposal for future research. *Social Theory & Health*, 12(2), 218-234.
- Glitin, L. N. (undated). *Research on Informal Caregiving: Gaps in Knowledge and Next Steps*: Johns Hopkins University Department of Community Public Health and Center for Innovative Care in Aging, School of Nursing Department of Psychiatry, Division of Geriatrics and Gerontology, School of Medicine.

- Goffman, E. (1961). *Asylum: Essays on the Social Situation of Mental Patients and Other Inmates*. Garden City, New York: Anchor Books, Doubleday & Company Inc.
- Goodhead, A., & McDonald, J. (2007). Informal Caregivers Literature Review: A report prepared for the National Health Committee Victoria University of Wellington.: Health Services Research Centre
- Griffin, R. W., & Moorhead, G. (2007). *Organisational Behaviour: Managing People and Organisations* (8 ed.). Boston, New York: Houghton Mifflin Company.
- Hasselkus, B. R. (1992). Physician and family caregiver in the medical setting: Negotiation of care? *Journal of Aging Studies*, 6(1), 67-80.
- Hauser, J. M., & Kramer, B. J. (2004). Family caregivers in palliative care. *Clinics in Geriatric Medicine*, 20(4), 671-688.
- Hayes, V. E., & Kjioux, J. E. (1984). The experience of stress in parents of children hospitalized with long-term disabilities. *Journal of advanced nursing*, 9(4), 333-341.
- Hayman, J. A., Langa, K. M., Kabeto, M. U., Katz, S. J., DeMonner, S. M., Chernew, M. E., . . . Fendrick, A. M. (2001). Estimating the cost of informal caregiving for elderly patients with cancer. *Journal of Clinical Oncology*, 19(13), 3219-3225.
- Hemsley, B., Balandin, S., & Togher, L. (2008). Professionals' views on the roles and needs of family carers of adults with cerebral palsy and complex communication needs in hospital| NOVA. The University of Newcastle's Digital Repository.
- Hennink, M., Hutter, I., & Bailey, A. (2010). *Qualitative research methods*: Sage.
- Herath, C. (2014). Study on factors leading to re-hospitalization and the care provided. *International Journal of Psychology and Counselling*, 6(2), 18-21.

- Hirst, M. (2002). Transitions to informal care in Great Britain during the 1990s. *Journal of Epidemiology and Community Health*, 56(8), 579-587.
- Homans, G. C. (1974). Social behavior: Its elementary forms.
- House, J. S. (1981). *Work stress and social support*. Reading, Mass: Addison-Wesley Pub. Co
- Hynes, G., Stokes, A., & McCarron, M. (2012). Informal care-giving in advanced chronic obstructive pulmonary disease: lay knowledge and experience. *Journal of clinical Nursing*, 21(7/8), 1068-1077 1010p.
- Ishikawa, H., Roter, D. L., Yamazaki, Y., Hashimoto, H., & Yano, E. (2006). Patients' perceptions of visit companions' helpfulness during Japanese geriatric medical visits. *Patient Education and Counseling*, 61(1), 80-86. doi:
- Janzen, J. M. (1978/1982). *The Quest for Therapy: Medical Pluralism in Lower Zaire*. London, England: University of California Press Ltd.
- Kasuya, R. T., Polgar-Bailey, M. P., & MPH Robbyn Takeuchi, M. (2000). Caregiver burden and burnout a guide for primary care physicians. *Postgraduate Medicine*, 108(7), 119.
- Kirk, S. (2001). Negotiating lay and professional roles in the care of children with complex health care needs. *Journal of advanced nursing*, 34(5), 593-602.
- Klopper, J. M., van Dyk, A., & Pretorius, L. (2015). The Experiences of the Elderly and Caregivers in Respect of Caring for the Elderly in Windhoek and Rehoboth Namibia: An Exploratory and Descriptive Study. *Open Journal of Nursing*, 5, 246-259.
- Knight, B. G., & Sayegh, P. (2010). Cultural values and caregiving: The updated sociocultural stress and coping model. *The Journals of Gerontology: Series B*, 65(1), 5-13.
- Kreitner, R., & Kinicki, A. (2006). Management of organizational behavior (concepts, theories & applications). *Pooyesh publication*.

- Laidsaar-Powell, R., Butow, P., Bu, S., Charles, C., Gafni, A., Lam, W., . . . Tattersall, M. (2013). Physician–patient–companion communication and decision-making: a systematic review of triadic medical consultations. *Patient Education and Counseling*, 91(1), 3-13.
- Laitinen, P. (1993). Participation of caregivers in elderly-patient hospital care: informal caregiver approach. *Journal of advanced nursing*, 18(9), 1480-1487.
- Lavdaniti, M., Raftopoulos, V., Sgantzios, M., Psychogiou, M., Areti, T., Georgiadou, C., . . . Sapountzi-Krepia, D. (2011). In-hospital informal caregivers' needs as perceived by themselves and by the nursing staff in Northern Greece: A descriptive study. *BMC nursing*, 10(1), 19.
- Leininger, M. M. (1991a). *Ethnonursing: a research method with enablers to study the theory of Culture Care*: NLN publications
- Leininger, M. M. (1991b). Selected culture care findings of diverse cultures using culture care theory and ethnomethods. *NLN publications*(15-2402), 345-371.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills: CA: Sage.
- Machinga, M. (2011). Religion, health and healing in the Traditional Shona Culture of Zimbabwe. *Practical Matters*, 4, 1-8.
- Maslow, A. (1954). *Motivation and Personality*. New York NY: Harber.
- Mattson, H. (2011). Linking Health Communication with Social Support *Mattson's Health as Communication Nexus*: Kendall Hunt Publishing Co.
- McCann, D., Young, J., Watson, K., Ware, R. S., Pitcher, A., Bundy, R., & Greathead, D. (2008). Effectiveness of a tool to improve role negotiation and communication between parents and nurses. *paediatric nursing*, 20(5), 14.



- Mcmillan, S. C. (2005). Interventions to facilitate family caregiving at the end of life. *Journal of Palliative Medicine*, 8(supplement 1), s-132-s-139.
- Meeker, B. F. (1971). Decisions and exchange. *American Sociological Review*, 485-495.
- Mikhail, S. L. B. (2002). Child marriage and child prostitution: Two forms of sexual exploitation. *Gender & Development*, 10(1), 43-49.
- Miles and Huberman. (1994). *Qualitative Data Analysis: An Expanded Source Book* (2nd ed.): Thousand Oaks CA: Sage.
- Morgan, D. G., Walls-Ingram, S., Cammer, A., O'Connell, M. E., Crossley, M., Bello-Haas, V. D., . . . Stewart, N. (2014). Informal caregivers' hopes and expectations of a referral to a memory clinic. *Social Science & Medicine*, 102, 111-118.
- Mulder, P. (2017). Bureaucratic Theory (Weber). . Retrieved 29/5/2017, 2017, from <https://www.toolshero.com/management/bureaucratic-theory-weber/>
- Mulemi, B. A. (2010). *Coping with cancer and adversity, Hospital ethnography in Kenya*. the Netherlands: African Studies Center.
- Muntarhorn, V. (1996). International perspectives and child prostitution in Asia. *Journal of International & Comparative Law* (Vol. 5:171)
- Myrdal, G. (1968). *Asian Drama: An Inquiry in the Poverty of Nations*. NY: Pantheon Press.
- Nahid, G. (2003). Understanding Reliability and Validity in Qualitative Research. *The qualitative report*, 8(4), 597-607.
- Neil A, Twibell, O., & Harris. (2010). Providing family friendly care- even when stress is high and time is short. *Am. Nurs.*, 5( 11), 9-12.
- Neuman, W. L. (2007). *Basics of Social Research: Qualitative and Quantitative Approaches* (2nd ed.). Boston: Pearson Int.

- Nortey, S. T., Aryeetey, G. C., Aikins, M., Amendah, D., & Nonvignon, J. (2017). Economic burden of family caregiving for elderly population in southern Ghana: the case of a peri-urban district. *International Journal for Equity in Health*, 16(16).
- Nyonator, F. (2007). Population and Health care Facilities in Ghana. In C. J. Mba & S. O. Kwankye (Eds.), *Population, Health and Development in Ghana: Attaining the Millenium Development Goals* (pp. 171-180). Legon, Accra, Ghana: Sub-Saharan Publishers.
- Oliver, D. P., Wittenberg-Lyles, E., Washington, K., Kruse, R. L., Albright, D. L., Baldwin, P. K., . . . Demiris, G. (2013). Hospice Caregivers' Experiences With Pain Management: “I’m Not a Doctor, and I Don’t Know if I Helped Her Go Faster or Slower”. *Journal of Pain and Symptom Management*, 46(6), 846-858.
- Oulton, J. A. (2006). The global nursing shortage: an overview of issues and actions. *Policy, Politics, & Nursing Practice*, 7(3\_suppl), 34S-39S.
- Parkes, K. R. (1982). Occupational stress among student nurses: anatural experinment. *Journal of Applied Psychology*, 784-796.
- Parsons, T. (1951). *The Social System*. New York: The Free Press.
- Parsons, T. (1960). Pattern variables revisited: A response to Robert Dubin. *American Sociological Review*, 467-483.
- Patton, M. Q. (2001). *Qualitative Research and Evaluation Methods*: Thousand Oaks, CA: Sage
- Pletzen Van E, M. H. (2013). Multi country research on community caregivers: the backbone of accessible care and support. South Africa report. *The Caregivers Action Network*.

- Quaicoe-Duho, R. (2015). Ghana reports general improvement in doctor ratio Retrieved 14 June, 2017, from <http://www.graphic.com.gh/news/health/ghana-reports-general-improvement-in-doctor-ratio.html>
- Radstake, M. (2000). Secrecy and Ambiguity: Home Care for People Living with HIV/AIDS in Ghana: African Studies Center.
- Reblin, M., & Uchino, B. N. (2008). Social and emotional support and its implication for health. *Current opinion in psychiatry*, 21(2), 201.
- Reck, R. R., & Long, B. G. (1985). *The Win-Win Negotiator*. Escondido: CA: Blanchard Training and Development.
- Reeves, E., Timmons, S., & Dampier, S. (2006). Parents' experiences of negotiating care for their technology-dependent child. *Journal of Child Health Care*, 10(3), 228-239.
- Remen, R. (2006). Including your patients in a culture of safety. In M. McGreevey (Ed.), *Patients as partners: How to involve patients and families in their own care*. (pp. 7-31). Oakbrook Terrace, IL: The Joint Commission.
- Rosenthal C, Marshall V, Macpherson AS, S., F., & (1980). *Nurses, Patients and Families*. New York:: Springer Publishing Co; .
- Sackey, B. M. (2009). Family Networking and Relationships in the Care of the Seriously Ill. In C. Oppong, P. Antwi & K. Waerness (Eds.), *Care of the Seriously Sick and Dying, Perspectives from Ghana* (pp. 188-210). Norway: Unifob Global.
- Sapountzi-Krepia, D., Raftopoulos, V., Sgantzios, M., Dimitriadou, A., Ntourou, I., & Sapkas, G. (2006). Informal in-hospital care in a rehabilitation setting in Greece: an estimation of the nursing staff required for substituting this care. *Disability And Rehabilitation*, 28(1), 3-11.

- Sapountzi-Krepia, D., Raftopoulos, V., Psychogiou, M., Sakellari, E., Toris, A., Vrettos, A., & Arsenos, P. (2008). Dimensions of informal care in Greece: the family's contribution to the care of patients hospitalized in an oncology hospital. *Journal of clinical Nursing*, 17(10), 1287-1294.
- Senah, K. A. (1981). *Kingroup in Health Management: A Case study in a Rural Community in Ghana*. Unpublished thesis.
- Senah, K. A. (2002). 'Doctor-talk' and 'Patient-talk' Power and Ethnocentrism in Ghana. In S. v. d. Geest & R. Reis (Eds.), *Ethnocentrism, Reflections on Medical Anthropology*. Amsterdam Aksant Academic Publishers.
- Sidel, V. W., & Sidel, R. (1981). Health Care and Medical Care in the US. In P. Conrad & R. Kern (Eds.), *The Sociology Of Health And Illness: Critical Perspectives*. New York: St.Martin's Press.
- Simons, H. (2009). Whose data are they? Ethics in case study research. *Case study research in practice*, 96-113.
- Solbjør, M., Rise, M. B., Westerlund, H., & Steinsbekk, A. (2013). Patient participation in mental healthcare: when is it difficult? A qualitative study of users and providers in a mental health hospital in Norway. *International Journal of Social Psychiatry*, 59(2), 107-113.
- Stake, R. E. (1995). *The Art of Case Study Research*. : Thousand Oaks
- Stavrou, V., Zyga, S., Voulgaris, S., & Sgantzios, M. (2014). Informal Care in a Formal Setting: the Case of a Neurosurgery Clinic in Western Greece. *International Journal*, 7(1), 102.

- Suleiman, A. A. (2007). Socio-cultural factors influencing the prevalence, care and support inHIV/AIDS among the Yoruba of Southwestern Nigeria. *African Journal of Health Sciences*, 14(1), 61-69.
- Tevington, P. (2011). Mandatory nurse-patient ratios. *Medsurg nursing*, 20(5), 265.
- Thomas, G. (2012). *How to do your Case Study: A Guide for Students and Researchers*. London: SAGE Publications Ltd.
- Toscan, J., Mairs, K., Hinton, S., Stolee, P., & Team, I. R. (2012). Integrated transitional care: patient, informal caregiver and health care provider perspectives on care transitions for older persons with hip fracture. *International Journal of Integrated Care*, 12.
- Trnobranski, P. H. (1994). Nurse practitioner: redefining the role of the community nurse? *Journal of advanced nursing*, 19(1), 134-139.
- Twigg, J., & Atkin, K. (1994). *Carers perceived: policy and practice in informal care*: McGraw-Hill Education (UK).
- Twumasi, P. A. (1975). *Medical Systems in Ghana*. Assembly Press, Accra: Ghana Publishing Corporation.
- Twumasi, P. A. (1988). socioeconomic Determinants of Child Health in Ghana. In F. Mackenzie & K. Ewusi (Eds.), *Research Issues in Child Health and Child Care, Proceedings of a Workshop held in Accra, Ghana, 22-26 September, 1986*. Ottawa, Ont., Canada: International Development Research Center.
- Tzeng, H.-M., & Yin, C.-Y. (2011). An appraisal of non-staff visitor involvement in bedside patient care in a specific hospital in the Midwest United States. *International Journal of Nursing and Midwifery*, 3(8), 91-98.

- Tzeng, H. M., & Yin, C. Y. (2008a). Family involvement in inpatient care: Are families there to offer support or are they concerned about quality of care? . *Clin.Nurs. Res*, 17(4), 297-311.
- Uchino, B. N. (2004). *Social support and physical health: Understanding the health consequences of relationships*: Yale University Press.
- Ugochukwo, C. G., Uys, Karani, Okoronkwo, & Diop. (2013). Roles of nurses in Sub-Saharan African region. *International Journal of Nursing and Midwifery*,, 5(7), 117-131. .
- Ujhely, G. B. (1977). *Determinants of the Nurse-Patient Relationship*. New York: Springer Publishing Company, Inc.
- van der Geest, S. (1972). *Family Dynamics in a Changing Society, A Case study of a Rural Ghanaian Society*. Thesis. Department of Sociology. University of Ghana, Legon.
- Wacharasin, C., & Homchampa, P. (2008). Uncovering a Family Caregiving Model: Insights From Research to Benefit HIV-Infected Patients, Their Caregivers, and Health Professionals. *Journal of the Association of Nurses in AIDS Care*, 19(5), 385-396.
- Wahyuni, D. (2012). The Research Design Maze: Understanding Paradigms, Cases, Methods and Methodologies. *JAMAR*, 10(1).
- Waliggo, J. (2006). Spiritual and Cultural Care. *A Clinical Guide to Supportive and Palliative Care for HIV/AIDS in Sub-Saharan Africa*. Global Partners in Care.
- Ward-Griffin, C., & McKeever, P. (2000). Relationships between nurses and family caregivers: partners in care? *Advances in Nursing Science*, 22(3), 89-103.
- Ward-Griffin, M. C. (1998). Negotiating the boundaries of eldercare, the relationship between nurses and family caregivers. University of Toronto. Unpublished Thesis.

- Washington, K. (2010). Zulu traditional healing, Afrikan worldview and the practice of Ubuntu: Deep thought for Afrikan/Black psychology. *The Journal of pan African studies*, 3(8), 24-39.
- Washington, K. T., Meadows, S. E., Elliott, S. G., & Koopman, R. J. (2011). Information needs of informal caregivers of older adults with chronic health conditions. *Patient Education and Counseling*, 83(1), 37-44.
- Wegner, W., & Pedro, E. N. R. (2009). Health conceptions under the perspective of lay caregiver women accompanying hospitalized children. *Revista latino-americana de enfermagem*, 17(1), 88-93.
- Welton, J. (2007). Mandatory hospital nurse to patient staffing ratios: Time to take a different approach. *Online Journal of Issues in Nursing*, 12(3).
- Whitlatch, C. J., Schur, D., Noelker, L. S., Ejaz, F. K., & Looman, W. J. (2001). The stress process of family caregiving in institutional settings. *The Gerontologist*, 41(4), 462-473.
- Williams, K., & Durrance, J. C. (2008). Social networks and social capital: Rethinking theory in community informatics. *The Journal of Community Informatics*, 4(3).
- Willis, J. W., & Jost, M. (2007). *Foundations of qualitative research: Interpretive and critical approaches*: Sage.
- Winefield, H. R., & Burnett, P. L. (1996). Barriers to an alliance between family and professional caregivers in chronic schizophrenia. *Journal of Mental Health*, 5(3), 223-232.
- Wise, S., Fry, M., Duffield, C., Roche, M., & Buchanan, J. (2015). Ratios and nurse staffing: The vexed case of emergency departments. *Australasian Emergency Nursing Journal*, 18(1), 49-55.

Wolff, J. L., & Roter, D. L. (2011). Family presence in routine medical visits: a meta-analytical review. *Social Science & Medicine*, 72(6), 823-831.

Yin, R. (2009a). *Case Study Research: Design and Methods* (4th ed.). California: Sage Publications, Thousand Oaks, .

Yin, R. K. (2003). *Case Study Research: Design and Methods* (3 ed.). Thousand Oaks,: CA: Sage.

Yin, R. K. (2013). *Case study research: Design and methods*: Sage publications.

Zucker, D. M. (2009). How to do case study research. Teaching Research Methods in the Social Sciences. Retrieved from [https://scholarworks.umass.edu/nursing\\_faculty\\_pubs/](https://scholarworks.umass.edu/nursing_faculty_pubs/)



## **APPENDIX 1**

### **INTERVIEW GUIDE FOR LAY CAREGIVERS**

1. Can you tell me about how you got into the hospital to provide care? Probe (name sickness)
2. What made you decide to provide care? (reasons or motives for services rendered)
  - A. Social factors, Cultural factors, Religious factors, Economic factors
  - B. Institutional
3. What type (s) of care do you provide? Physical, emotional, financial etc
4. How would you say taking care of your relation has affected your health? (impact of care giving on caregiver eg. physical and emotional strain)
5. What are some of the difficulties you experience as a caregiver? (Probe)
6. How will you assess the care you provide with those that the professionals provide? (perception of the value of care provided in comparison with the professionals)
7. What assistance, if given to you, would make it easier for you to look after this patient?
8. Will you opt for a paid caregiver? Why?
9. What do you think people will say about you if you did not come here?
10. What recommendation can you give to the government or hospital authority for improvement in care delivery?

## **APPENDIX 2**

### **INTERVIEW GUIDE FOR NURSES AND DOCTORS**

1. What is the normal/ideal routine care that must be given to the inpatients? (Probe)
2. What are some of the challenges you face in care delivery in the ward?
3. Why do you think caregivers stay around? (Probe)
4. What kind of care do lay caregivers render to inpatients? Eg. their usefulness or otherwise
5. Will you advocate for the inclusion of lay caregivers in care delivery system at the hospital and why?
6. How do you share responsibilities with lay caregivers? (Probe)
7. Some caregivers complain of negligence and suggestions nurses should be assign to patients and rooms rather than all of them moving from one room to the other. What can you say about this?
8. What measures have you put in place to assist these caregivers? (Probe)
9. Since when has this phenomenon of lay caregiving started in the hospital?

### **APPENDIX 3**

#### **INTERVIEW GUIDE FOR PATIENTS**

1. Which people have supported you so far? Probe.
2. What kind of supports/care have you received from the professionals?
3. What expectation(s) do you have about the health professionals' support? (what the patient wanted health professionals to do)
4. Can you think of the one person or persons besides a health care provider who helps you the most with your condition?
5. What kinds of care do you receive from your lay caregiver (s) Probe
6. What can you say about the support given by your lay caregiver? Probe
7. What have been the challenges so far in getting help? (talk about institutional, social, economic etc factors)
8. Please tell me about your experience in the ward (relationship with health professionals, other patients and visitors)

## **APPENDIX 5**

### **OBSERVATION PROTOCOL FOR HEALTH PROFESSIONALS, LAY CAREGIVERS AND FAITH HEALERS**

The study will employ non participant observation technique to collect data to complement the data collected using the interview guide and will take the following into consideration:

1. Time of activities (visiting, time of leaving, time of attending to patients etc)
2. Type of visitors (relatives, church members or groups, friends and co-workers)
3. Actual activities undertaken by participants

**APPENDIX 6**

**SOCIOLOGY DEPARTMENT**

**UNIVERSITY OF GHANA, LEGON**

**CONSENT FORM FOR RESEARCH PARTICIPANTS**

I ..... of .....

hereby agree to participate in this study to be undertaken by Ms. Gladys Agbenyefia

I understand or agree that the purpose of the research is to explore the socio-cultural and institutional factors that influence lay caregivers to provide care in a hospital environment and how they negotiate their roles with the health professionals.

I agree that:

1. The information I provide will be coded and my name and address kept separate from it.
2. Information provided will not be made public in any form to reveal my identity to a third party and research results will not be released to any person except at my request.
3. Results will be used for academic research purposes in the form of thesis.
4. I am free to withdraw my participation without suffering any negative consequence during the study and any information obtain from me will not be used.

.....

Signature of volunteer

.....

Date

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

.....

Name of witness

.....

Date

.....

Signature of witness

The contact details of the researcher are: [gladysmawufemor@gmail.com](mailto:gladysmawufemor@gmail.com) , Mobile: 0244799194

**APPENDIX 7**

**DEPARTMENT OF SOCIOLOGY  
UNIVERSITY OF GHANA, LEGON  
P. O. BOX LG 65  
LEGON**

**TRANSLATORS/TRANSCRIBER'S CONFIDENTIALITY SHEET**

**Title of Research Project:** The interface between the Health Professionals and Lay Caregivers at the Koforidua Central Hospital

**Researcher:** Gladys Agbenyefia, PhD student, University of Ghana, Legon.

I am a research student from the department of sociology, University of Ghana, Legon. I am carrying out a study on health professionals and lay caregiver and I would like you to translate/transcribe my individual interviews that were done in Twi/Ga/Ewe/English.

**Confidentiality/Anonymity**

Participants name will not be recorded on the tape or paper. Instead, a number or pseudonym will be applied. It is imperative for you to keep the information to yourself without disclosing it to other people not involved in the study.

This confidentiality requirement was explained to me by-----  
I agree to keep all information confidential.

-----  
Signature of transcriber/translator

-----  
Date

-----  
Witness

-----  
Printed Name

-----  
Printed Name

-----  
Signature of investigator

-----  
Date

-----  
Printed Name