UNIVERSITY FOR DEVELOPMENT STUDIES

QUALITY OF LIFE OF PATIENTS AND THEIR CAREGIVERS: AN ASSESSMENT OF THE PERCEPTIONS OF SUFFERERS OF CHRONIC DISEASES IN THE BOLGATANGA REGIONAL HOSPITAL

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BY

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JULY, 2017

DECLARATION

I hereby declare that this thesis is the result of my own original work and that no part of it has been presented for another degree in this university or elsewhere:

……………………………   ………………………………

AMOAH ANETU DAMIEN   **DATE**

(UDS/CHD/0061/12)

I hereby declare that the preparation and presentation of the dissertation were supervised in accordance with the guidelines on supervision of thesis laid down by the University for Development Studies

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DR. THOMAS AZONGO   **DATE**

(SUPERVISOR)

ABSTRACT

The main objective of this study is to assess the Quality Of Life (QOL) and illness perceptions of patients and their caregivers living with chronic diseases.

Chronic Diseases (CD) are progressive conditions with both motor and non-motor symptoms that can have a profound impact not only on the patients but also on family members who often adopt the role of caregivers. They place significant demands on the caregiver, as they take on more daily tasks and increasingly provide physical, emotional, and economic support. The overall aim of this thesis was to assess the Quality Of Life (QOL) and illness perception of patients and family caregivers living with chronic diseases. A facility-based cross-sectional study was conducted in the Upper East Regional Hospital. Quantitative method was used to collect data. Purposive sampling was used to select the respondents for this study. The study recruited 144 patients from four chronic diseases attending their weekly clinic sessions. Also, 144 family caregivers were interviewed on the illness perception of their relatives. Caregivers of the patients had greatly different opinions about the illness perception (p=.003.This implies that different conditions present different perceptions. Patients with Mental diseases (M=169.17, SD=20.68) have differences than Diabetic patients (M=155.47, SD=10.82). There was no significant differences among the four selected diseases on patients' quality of life as also applied to the subscale levels too (p=.005). HIV/AIDS caregivers have more significant scores than Diabetic caregivers. For causes of illness, it was revealed that mental caregivers have more significant scores than HIV/AIDS caregivers (p=.000). In total, mental caregivers have more significant scores than HIV/AIDS caregivers and Diabetes caregivers (p=.000). There was no significant difference between the four diseases (p=.537) of caregivers on quality of life (QOL) and at the subscale levels , except for Life Activities QOL which revealed that

Diabetes caregivers have more significant scores than HIV/AIDS caregivers (.008). Partners feel a heavy responsibility and their involvement in providing care has an enormous impact on their quality of life.

DEDICATION

To my wife, children and all those who supported me materially and spiritually.

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My appreciation goes to the Medial Director, Hospital Research committee and all the staff of the hospital for their support in writing this report during the entire period of the Thesis. I am also grateful to Dr.Thomas Azongo for his assistance and supervision in various ways that has enabled me to complete this programme successfully. I further extend my thanks to the data collectors and patients as well as their caregivers for their support and acceptance to have been part of this all important exercise**.**

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ACRONYMS AND ABBREVIATIONS

AIDS:	Acquired Immunosuppressive Syndrome
ANOVA	Analysis of Variance
ART:	Anti-Retroviral Therapy
CDS:	Communicable Diseases
CSM:	Common Sense Model
FNDS:	Functional Neurological Diseases
HIV:	Human Immune Virus
HRQOL	Health Related Quality Of Life
IPQ	Illness Perception Questionnaire
NCDS	Non-Communicable Diseases
NDS:	Neurological Diseases
O&G:	Obstetrics and Gynaecology
PLHIV	People Living With Human Immune Virus
QOL:	Quality Of Life
SPSS:	Statistical Package for Social Sciences
TIAs:	Transient Ischemic Attacks
WHO:	World Health Organization
WHOQOL	World Health Organization Quality Of Life

DEFINITION OF KEY TERMS

Quality of life: The standard of health, comfort, and happiness experienced by an individual or group.

Chronic diseases: Diseases that cannot be prevented by vaccines or cured by medication, nor do they just disappear.

Illness Perceptions: These are cognitive and emotional representations of people's illness.

CHAPTER ONE

INTRODUCTION

1.0 Background

Quality of life research is increasingly being directed at both the impact of the social environment on the quality of life (QoL) of chronically ill individuals, and at the toll the illness exacts on the QoL of close family members (Martire et al, 2004). One of the most influential members of the social network of chronically ill individuals is the spouse. Research conducted in chronically ill individuals and their healthy spouses revealed that the spouses' role problems (Manne & Zautra, 1989), their unsupportive behaviour (Manne & Glassman, 2000), and the marital relationship itself are some of the factors influencing patients' QoL (Northouse et al 2000).

Quality of Life is a multi-dimensional concept of which definition remains controversial. It is conceptualized in terms of an absence of pain or an ability to function in day to day life. Further, as health is generally cited as one of the most important determinants of overall quality of life, it has been suggested that QoL may be uniquely affected by specific disease processes such as AIDS.WHO reports Non Communicable Diseases (NCDs) which Chronic Diseases (CDs) are part, to be by far the leading cause of mortality in the world, representing over 60% of all deaths (Giri et al., 2013).

World Health Organization (WHO) defines health as not merely the absence of disease or infirmity, but a state of complete physical, mental and social wellbeing (World Health Organisation, 1985). The definition of Quality of Life (QoL) is more complex. According to WHO, QoL is defined as individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns (WHO, 1996). Chronic Diseases (CD) are debilitating diseases affecting about 10%-15% of the population.

According to a report by the Department of Health (2012), the number of people with three or more long-term conditions is predicted to rise from 1.9 million in 2008 to 2.9 million in 2018. Multi-morbidity is more common among deprived populations-especially those that includes a mental health problem (Barnett et al, 2012) and there is evidence that the number of conditions can be a greater determinant of a patient's use of health service resources than the specific diseases (Barnett et al, 2012).

They are progressive conditions with both motor and non-motor symptoms that can have a profound impact not only on the patients but also on family members who often adopt the role of a caregiver. Chronic diseases can place significant demands on the caregiver, as they take on more daily tasks and increasingly provide physical, emotional, and economic support. It is recognized that caregivers of people with CDs have a reduced quality of life (QoL) where their social activities and work schedules reduce to be more involved in caring. Caregiver spouses are less likely to spend time outside of the house or take a holiday than non-caregiver spouses, and older spousal caregivers often have to face age-related challenges themselves. The trend toward community-based care, along with advances in medical technology, has resulted in increased numbers of individuals with complex healthcare needs being cared for at home by their families. This shift from hospital to community care places increased demands on family caregivers. Families are now providing long-term care for chronically ill people with a variety of conditions. Caregiver research has, for the most part, explored burden, stress, and depression as outcomes of care giving (Canam & Acorn, 1999) but very few on their QoL.

Numerous studies assessing the impact of chronic disease on the partner/caregiver are cross-sectional and focus on the elderly or mental patients. In general, the burden of care seems to greatly affect the caregiver's quality of life. For example, analyzing reports from 256 carers (enrolled from a random sample of 1079 elderly individuals), Jones and Peters (1992) came out with facts that caring for a helpless individual worsened health, detract social and family life and magnify their anxiety ,stress and depression levels.

1.2 Problem statement

The number of reported new cases of chronic diseases in outpatient public health facilities in Ghana increased more than ten-fold between 1988 and 2013. The number of cases increased from 49,087 in 1988 to 505,180 in 2013. Diabetes also increased from 1.7% of total reported cases outpatient cases in 1988 to 4.0% of total outpatient cases in 2014. Diabetes, stroke and hypertension were also reported to be the leading causes of hospital admissions and mortalities (Ghana Health Service, 2014) These cases have been attributed to the changing lifestyle at the Ghanaian and also increasing urbanization and physical inactivity.

In the Bolgatanga Regional Hospital, the number of reported cases of chronic diseases; HIV/AIDS, hypertension, stroke and diabetes among the residents at all levels in the Municipality increased from 548 in 2011 to 595 in 2012 for in-patient and 1020 in 2011 to 1419 in 2015 for out-patients (2016 Annual Report , Regional Hospital, Bolgatanga). The economic impact of chronic diseases is very enormous especially on the budget of the health sector institutions and at the individual level. Chronic diseases do not only affect individuals but families and groups because it demoralizes relatives of the victims. Apart from the fact that these diseases affect the budgets of families they also take away the joy of families because of the fear that there is no cure or medication for these diseases. There is however very little scientific data on the quality of lives of people who are living with these chronic diseases. This study therefore seeks to assess the quality of life of people living with chronic diseases seeking care at the Bolgatanga Regional Hospital.

1.3 Research questions

The following are the research questions being investigated in this study based on the problem statement as well as reviewed literatures:

1. Are patients' illness perception significantly different from caregivers' perception?
2. Do different group of patients have differences in their illness perception?
3. Do different group of patients have significantly different quality of life?
4. Do different group of caregivers have significantly different perception about their relatives/neighbours' illness?
5. Do different group of caregivers have significantly different quality of life?

1.4 Main/General objective

The main objective of this research is to assess the Quality Of Life (QOL of patients and their caregivers: An assessment of the perceptions of sufferers of chronic diseases in the Bolgatanga Regional Hospital.

1.4.1 Specific Objectives

1. To derermine whether patients' illness perception will be significantly different from caregivers' perception.
2. To determine whether different group of patients would have different perception about their illness.

3. To explore whether different group of patients would have significantly different quality of life.
4. To determine whether different group of caregivers would have significantly different perception about their relatives/neighbours' illness
5. To determine whether different group of caregivers would have significantly different quality of life.

1.5 Significance of the Study

This study is apt as it has come at a time when issues bordering on quality of healthcare are on the increase in Ghana. It is expected that the results of this study would throw more light on the dynamism and pattern of healthcare in general; specifically the quality of life of chronically ill patients and their carers' as well as their illness perception. Hence, it would equip the Ghanaian populace with useful and helpful information on psychosocial issues in healthcare.

The study would also acquaint health professionals and other stake holders with techniques to identify potential psychosocial challenges during healthcare delivery by providing valuable information on certain signals to look out for in patients and their relatives seeking healthcare. It would also facilitate or strengthen the use of multidisciplinary team in healthcare so as to tackle patients' problems holistically.

1.6 Scope of the Study

This study specifically focused on all patients who attended the listed clinics during the study period who are currently suffering from diabetes mellitus, HIV/AIDS, stroke, and mental illness as well as their caregivers for more than a year. These individuals, as part of their routine have to report to a medical officer at most monthly for check-up purposes. Hence, all the recruitment and data collection procedures were at the Regional Hospital, Bolgatanga where they report due to availability of specialists.

1.7 Conceptual Framework of Quality of Life (QoL)

A model of Health Related Quality of Life (HRQoL) might help us better understand the conceptual frame work of quality of life. Wilson and Cleary (1995) described a conceptual model of HRQoL that provides a theoretical approach to conceptualizing HRQoL as a multidimensional construct which integrates biological and psychological aspects of health outcomes. This model consists of five different levels namely, physiological factors, symptom status, functional health, general health perceptions and overall QoL. It has been widely applied to different populations, including patients with cancer, arthritis, Parkinson's disease and HIV. It is indicated that symptom status, functional health, general health perceptions, and overall QoL are dimensions of HRQoL (Figure 1)

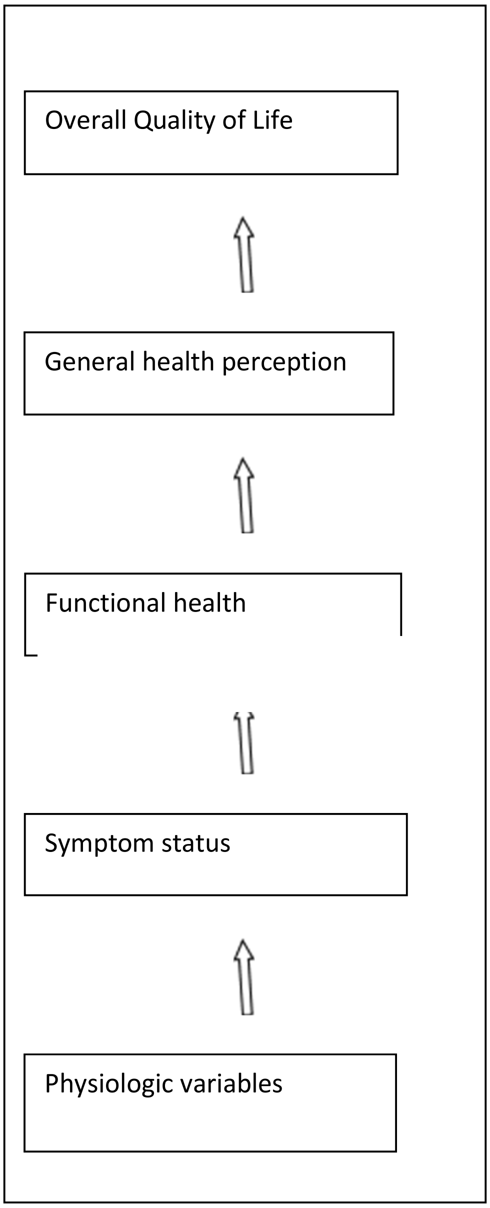


Figure 1. The pathway in the Wilson and Cleary (1995) HRQOL conceptual model.

Figure 1 depicts the hypothesized linkages between the dimensions. The model suggests that physiological variables influence symptom status, symptom status influences functional health, functional health influences general health perceptions and general health perceptions Influence overall QoL. The evaluation of physiological variables focuses on cells, organs, and organ systems, though the assessment of symptom status shifts to the organism as a whole. Functional health is defined as the ability of an individual to perform and adapt to one's environment, measured both objectively and subjectively over a given period. General health perceptions reflect an integration of all health concepts previously reviewed, additional to mental health and they are by definition subjective ratings.

Although health perceptions are personal beliefs, overall QoL has been described as the discrepancy between a person's expectations or hopes and his present experiences. Wilson and Cleary model was later revised by Ferrans et al (2005). The revised model was developed in order to explain the relationships of clinical variables that relate to QoL by linking individual characteristics with environmental characteristics.

1.8 Organization of the Study

This particular research study is organized into six chapters. Chapter one examines the background information to chronic diseases especially those under study, highlighting the statement of the problem and justification, research questions, research objectives, relevance of the study, scopes of the study, and conceptual framework. Chapter two thoroughly examines literature specifically, related studies to the subject areas. Chapter three comprises of the methodological procedures used for the data collection. This includes the study design, sample size and characteristics, sampling technique, research variables, data collection and study instrument, quality control, and research ethics. Chapter four deals with the analyses and interpretation of the results of the data collected whilst chapter five discusses the key findings of the study. The last but not the least chapter, chapter six, presents the conclusions as well as the recommendations made by the researcher. Specifically, it brings to the fore the novel contributions and main findings of this thesis, methodological limitations, as well as future directions of this research area.

CHAPTER TWO

LITERATURE REVIEW

2.0 Introduction

This chapter reviews relevant literature in relation to the study. The review is presented under the following headings; the meaning of illness and disease, perception of illness and disease by patient and physician, the impact of chronic illness on caregivers/partners, perceptions about illness, and personal understanding of illness.

2.1 **The meaning of illness and disease**

The differences in getting the meaning of the concepts “illness” and “disease” is debatable, particularly in Sweden as the Swedish language lacks the concept of or word corresponding to “illness” and therefore the word “disease” is used for both “illness” and “disease”. One of the most classical theoretical works on illness experiences is Kleinman’s (1988) monograph “The illness narratives”. Most researchers have contended that illness experiences are fundamentally different from the disease perspective (Fabrega, 1974; Eisenberg, 1977; Jennings, 1986; Conrad, 1987; Bury, 1991; Toombs, 1993; Atkinson, 1995; Conrad & Bury, 1997).

The disease concept is based upon “the medical model”, which is concerned with viewing the non-diseased body as “normal” and disease as a deviation from the patient’s natural state or from statistical norms, independent of particular experiences or circumstances (Lawrence, 1994). Kleinman (1988) defines illness as a social perspective that is a dynamic process in which sick persons, their family and their social network perceive, live with and respond to symptoms and disability.

Toombs (1995) had an explanation that one's experience of illness is relative to losing bodily functions or not functioning the way before and is based on how the disease is understood in each passing daily life.

According to Conrad (1987), "illness" is a critical time of being ill and has to do with what we go through in life, do and what we feel when we are ill. The experience of illness is best studied by interviews, with questions such as, "What felt wrong?", "Why did you seek care?", "How can you manage this situation?" and "How is your life affected by the illness?"

According to Bury (1991), the term "illness" refers to the experience, feelings and sensations attitudes towards, a physical and/or psychological and social malfunctioning or suffering. Illness is within the human being. It includes recognizing that one's body processes are disturbed and therefore must take appropriate steps to curb the situation, such as seeking treatment.

Disease, on the other hand, is not only associated with humans. The term "disease" is technically defined as a disturbance or deviation from the biological norm, which is scientifically diagnosed (Lupton, 1994, p 93). This definition does not imply that disease is an objective state, since it is categorized and influenced by social, historical and political contexts.

The physician Eisenberg in his popular study in 1977 gave the differences between disease and illness stating that patients suffer "illnesses" whist physicians diagnose and treat "diseases". He further stated that whereas disease is a deviation in the structure and function of the body's organs and systems, illness is an experience of disvalued changes in states of being and social functions. Cassel (1976) in his study of interactions between doctors and patients emphasized the ways in which diseases and body parts are known in simple language. He found out that diseases and symptoms are frequently described using common terms such as "it" or "the disease" rather than personal pronouns such as “my” or “I”. This usage may signify that patients do not always view their disease as part of themselves, but as entities that exist apart from themselves.

2.2 Perception of illness and disease by patient and physician

The philosopher Kay Toombs (1993, p 1) argues that illness and disease are experienced from different perspectives, namely from the point of view of the doctor and that of the patient.

The patient’s and health professional’s experiences are classified into five categories, the first being the *focus*. The physician makes preliminary diagnosis focusing on processes, signs and symptoms that resemble classical cases of diseases; the patient usually focuses on effects on daily life and function. *Attitudes* are the second category in which the two parties have differences. The doctor may appear naturalistic to a scientific abstracts, the patient represents the natural attitude, in terms of which life is taken for granted and actions are based on ones ideas, practical and sensible. The third dimension is *time*. The doctor uses a realistic time scale to measure and define the patient’s state. The patient’s experience of time, especially during suffering, is subjective. The fourth perspective has to do with *relevance*, here the process of the disease and the clinical information being important in the scientific work of the professional. By contrast, the patient views of illness as more relevant in his or her daily life. The last category of the different life-perspective of the doctor and patient is the striving for a *common communication*, which does not imply that the language used is a common basis. The physician recalls the patient’s experiences on the basis of usual cases while the patient describes the problems as unique and specific events with existential elements. The words that are used may illustrate the different perspectives. The word “diagnosis”, which is frequently used among physicians, corresponds to the word “exploring” used by the patient, containing a confirmation that the experiences one has had are appropriate. Giving “treatment” corresponds with getting a "cure", or returning to the life one had before. "Prognosis" corresponds to "prediction", meaning to know what is likely to happen to oneself in the future. These differences are not merely based on different levels of knowledge, but particularly on a difference between lived experience and the *scientific conception or paradigm* (Toombs, 1995).

2.3 Impact of chronic illness on partner/caregiver

Numerous studies assessing the impact of chronic disease on the caregiver have often focused on the elderly or mental health patients. In general, burden of care does seem to worsen carers' quality of life. For example, analyzing reports from 256 carers (enrolled from a random sample of 1079 elderly individuals), Jones & Peters (1992)found that caring for an incapacitated individual worsened health, impaired social and family life and increased stress, anxiety and depression.

Partners of stroke patients found that the dependence physically, thinking and communication deficits and as well as psychological symptoms of their spouses meant that the spouse 'was not the same person'. This led to partners' describing a decrease in their marital satisfaction although, by contrast, most patients claimed they had no marital difficulties (Bethoux, et al, 1996).

The outcome of individual differences in QOL after stroke is also very important. While many factors affect long-term stroke recovery, two socio-demographic factors race and gender appear to be particularly important, although the mechanisms behind these differences are not well understood.

According to Gargano, & Reeves, (2007); Patel et al, (2007) and Petrea et al, (2009), women and African Americans tend to have poorer QOL outcomes after stroke than men and Whites.

Lack of a caregiver to facilitate access to care may explain worse outcomes observed for women and African American stroke survivors. For example, a study by Hackett & Anderson, (2005) concluded that social factors (i.e., living alone, social support, social isolation) were consistently related with post-stroke QoL. Understanding the extent and weight of the effects of stroke on quality of life has important implications for public health. Quality of Life outcomes are consistently seen as reflecting clinically significant indicators that are important to patients and families (Kissela, 2006).

Müller-Nordhorn, et al, (2005) also identified one study that has attempted to explore the magnitude of QoL changes before and after stroke. In this research, patients experiencing transient ischemic attacks (TIAs) or strokes who reported to an emergency room were asked to reflect backwards their QoL before the stroke (using the SF-12) and then either the stroke survivor or their carers completed a SF-12 one year later.

In all studies examining the role of spousal illness perceptions for patient outcomes, researchers have concentrated on the degree of differences in patients' and spouses' illness perceptions as an indicator of patient outcome, thereby ignoring alternative possible relationship patterns between spouses' illness beliefs and patient outcome. Research results from Figueiras and Weinman (2003) showed that not only similar positive perceptions in couples, but also conflicting perspectives were predictive of lower levels of disability (as compared to similar negative perceptions). This suggests that it might be more important that at least one member of a couple has positive perceptions.

Bury's (1982) concept of 'biologiical disruption' refers to disruptions that illness cause to the physical body and the life pathway of the sufferer. A person's inability to perform everyday tasks including self-care creates psychological strain, which can lead to social isolation including depression (de-Graft Aikins, 2005). Individuals are members of households, and households are organized in a way that combines both contributions and needs across members. Households that include people with chronic illness must include contributions to account for illness-related changes in employment, and redistribute resources relative to increased needs of members with NCDs.

2.4 Personal understanding of illness

Explanatory models and personal models are concerned with finding out how people understand their illness, in other words, identifying the characteristics that people with diseases believe to be central to their experience of an illness and its management. The concept of "explanatory models" is used for understanding illness from both a professional and a lay point of view, while "illness representation" exclusively focuses on the patient's beliefs about illness (McSweeney et al, 1997). Personal models include emotional manifestations (e.g. worries, fear) to the disease and treatment, a component that is lacking in many other reports on beliefs about health and illness (Poss & Jezewski, 2002). In this thesis I will use the concept "personal understanding of illness" to refer to the complex intertwining of thoughts, feelings, explanations and understanding involved in the illness perspectives. The following components are frequently reported to be important in personal explanatory models: identity/label, cause, consequences, time line, and control/cure (Kleinman, 1988; Lau et al, 1983).

Among adult people with diabetes, beliefs about control and cure have been found to be indicative of dietary and exercise management (Hampson et al, 1990; 1995).

Francioni & Silva (2002) interviewed people with diabetes in order to understand the process of accepting to live with diabetes. They highlighted four categories, namely: "to find out was terrible"; "it is hard to live with it"; "but you have to accept it"; and "it is possible to have a good life, even with diabetes". Paterson et al (1999) describe how patients with diabetes type 1 develop a totally transformed self, separated from the body and the illness. The transformation is, according to the authors, both an outcome of managing an illness-related challenge and a trick to mediate the impact of illness. Nyhlin et al (1987) studied well-adapted patients with diabetes type 1 without any consequences despite a long duration of the disease, and report that their perspectives of dealing with diabetes can be divided into the following groups: "up to oneself"; "walking a fine line"; "the days are numbered";" not ill but having a disease"; "being dependently independent".

Koch et al (1999) in a study among women with diabetes type 2 found out that women experience diabetes negatively, as bringing only limitations. They often have to cope with depression and fatigue, with social complications such as being set apart, and found living with diabetes stressful because it demands that they are constantly alert. The interviewed women talked about a poor quality of the doctor-patient relationship, compulsion used by the doctors to ensure adherence to biomedical treatment regimens and also, failure on the part of the doctor to perceive problems from the patient's point of view as well as an attempt to put aside and ignore the patient's experiences in relation to management of her diabetes (Koch et al, 1999).

Well-being and quality of life have been recorded to increase, at least in the short term, following programmes supporting self-management (Steed et al, 2003). Quality of life as well as health outcomes has also been shown to increase as a result of one-to-one nursing care after education among persons newly diagnosed with diabetes type 2, a multi-method that Whittemore et al, (2001) view as cost-effective. Larme and Pugh (1998) point out the importance of long range goals leading to both well-being and metabolic control among patients, not merely metabolic control.

The effect of strategies put in place, educational or psycho-social, aimed at self-management and improved glycaemic control is, however, reported to be inconclusive. Moreover, in many cases the interventions are reported to be poorly described and the metabolic effects in the longer term are discouraging (Norris et al, 2002). In particular, there is lacking evidence of efficacy of olden day moral education programmes alone for improving glycaemic control (Brown, 1999; Griffin, 1999; Norris et al, 2002).

Despite these facts, insight into diabetes is generally seen as necessary for self-management but is not sufficient to effect behaviour change or improved clinical outcomes in diabetes (Coates & Boore, 1996) even if some studies report effects of traditional education on glycaemic control (Parchman et al, 2003). Also, some treatment interventions such as education given in small groups and focusing on impacting knowledge in coping skills have been reported to improve glycaemic control in the short term (Rubin & Peyrot, 1999; Tattersall, 1985).

Organizational interventions that improve regular prompted periodic review of patients are also reported to improve diabetes management and glycaemic control in the short term (Renders et al, 2002). A current review (Ellis et al, 2004) concludes that face-to-face interaction, cognitive reframing, and self-management programmes with exercise components are pre-requisite for metabolic control. Follow-ups by support groups are also reported to be necessary for more long-duration outcomes (Scott et al, 1984; McNabb et al, 1993; Gilden et al, 1989). Larme and Pugh (1998) point to the significance of questioning not only the patient's knowledge but also, the caregiver's attitudes and knowledge, which has to be updated with latest developments.

2.5 Perceptions about Illness

2.5.1 Sickness as a Social Reality

An ill patient is not only suffering physically, but is also in the midst of an increasingly intense emotional experience. The understanding of illness in the social context of a patient's life can be extremely beneficial when considering disease treatments. Those with competing diseases can actually have huge different illness experiences due to external social factors. Social pressures can lead to health-related behaviors that are not in tangent with the management needs of the disease. Illness affects every aspect of a person's life, and this reality must be taken into account by medical intervention programs (Rich et al, 2010)

Stigmas surrounding diseases such as AIDS can delay individuals from getting tested and can reduce devotion to treatment, which therefore increases the number of infections. An individual's response to stigma is significant: those who manage to resist it (regardless of poverty and discrimination) can achieve self- image by accepting their diagnosis and finding a way to lead a happy life despite their illness, while those who fall to the stigma are more worried, upset, and sad. Through illness narratives, it has been established that an individual may be capable of withstanding stigma once they are able to establish a new identity and social role. Those living in poverty, or those who have little family support, may not have access to the resources that may assist in the formation of this new self. Therefore, patients who are socially isolated by illness may have a decreased chance of establishing such a role, in addition to having the highest risk of transmission, re-infection, and misuse of medication. Community groups should focus the most on this group of people, providing both social support and the medical treatment resources necessary for reformation of identity and resisting social stigma (Goudge et al, 2010)

Julius, a 33 year old AIDS patient, demonstrates how support from family and other social groups is crucial, as he asserts: *"Being accepted by my family has meant a lot to me. I don't think I would have made it without them in my life."* This confidence that stems from social support allows Julius to view his illness in the most positive light possible and to consciously adhere to his treatment schedule (Ibid.)

Phanuel and Paulinah, a married couple in their mid-thirties, are both HIV-positive. The differences in how they dealt with their diagnosis highlight how social treatment of HIV can greatly affect the patient's happiness and life satisfaction. Phanuel's initial reaction was to act angry towards everyone and to sideline himself from his friends due to fear that they would judge him. In contrast, Paulinah chose to be open and frank about her status, which permitted her to facilitate friendships with other HIV positive community members. Although the family ultimately decided to move to a new area in order not to be known, the different approaches demonstrated by each spouse reveal how stigma can either be life-changing or inhibitive (.Goudge et al, 2009).

2.6 The Role of Illness Perceptions

Illness perceptions are the organized cognitive and emotional characteristics or beliefs that patients have about their illness. These perceptions have been found to be important predictors of behaviour and have been associated with a number of important outcomes, such as treatment compliance and functional recovery (Rowbothan et al, 1998, Mant et al, 2000). There is a consistent pathway to the way patients organize their perceptions of illness. Illness perceptions generally contain an identity component, which includes the name of the illness and the frame of symptoms that the patient believes are associated with the condition. They also contain beliefs about the cause of the illness and how long it will last. Furthermore, illness perception components include beliefs about the personal implications of the condition for the patient and their family, as well as the extent to which the illness is changeable to personal control or to control by treatment**.** According to Tetteroo et al, 1998), patients' beliefs about their condition are often different from those of the professional. Generally, medical staffs are usually making their own views about the patient’s condition during clinical consultations and encounters. Secondly, patients' perceptions do vary. Sometimes, patients with the same medical condition or injury can hold very divergent views of their illness.

Following an impressive set of studies conducted by Frostholm et al, (1993) that highlighted the importance of understanding illness perceptions in primary care patients. The studies involved 28 Danish general practices and 1785 patients attending with a new health problem. Patients completed assessments of illness perceptions, physical functioning, and distress prior to seeing the doctor as well as ratings of satisfaction with the consultation following their appointment. The first study found illness perceptions - in particular, unclear about their symptoms and emotional distress about the illness - were significant signals of decreased patient satisfaction with the consultation.

A related study demonstrated strong relationship between illness perceptions and the later use of healthcare. (Felder-Puig et al, 2000*)*. Primary care patients who related more symptoms with their illness, and who had longer timeline and more severe illness consequence beliefs used significantly more healthcare in the 3 years leading up to the study, as well as in the 2-year follow-up period. These three illness perceptions may be crucial in predicting future healthcare and the study suggests that discussions with patients about their thoughts and ideas about their illness could help clear up myths and reduce the risk of the health problem developing into a later chronic condition. This study is in line with a recent investigation of predictors of healthcare use in patients with medically unexplained symptoms attending neurology, cardiology and gastroenterology clinics (Barr et al, 1993). The results also showed that the number of symptoms the patient associates with their condition or illness identity was indicative of future healthcare use in the following 6 months. These studies points out the importance of the patient's beliefs and emotional responses to their symptoms and illness as key factors influencing satisfaction with the consultation and the subsequent use of health care.

The diagnosis of any chronic illness challenges individuals with a collection of tasks necessary for both physical and psychological adjustment. Adjustment may involve acceptance of a certain amount of loss of function. It may also require the accumulation of new skills and changes to daily activities in order for the patient to manage the symptoms of the illness or cope with the demands of treatment (Feeny ***et** al. 1993)*. As such, chronic illness places a mighty burden on the individual and can have a significant impact on their quality of life. From earlier research it is clear that the illness perceptions of individuals are highly indicative of determining outcomes and adjustment in a number of medical conditions (Rowbothan et al; 1998, Mant et al, 2000)

Patients suffering from type 2 diabetes, perceptions of shorter duration and greater treatment effectiveness were pointers to greater diabetes self-management (Saigal et al, 1996). There are a number of potentially exciting areas of emerging research with illness perceptions that can be explored.

Research shows that patient’s knowledge about their medications and reasons for accepting treatment are motivating factors for them to start antiretroviral treatment for their HIV infection (Sneeuw et al, 1997*)* and also to adhere in a number of conditions (Addington-Hall et al, 2001, Hodgkins et al, 1985; Au et al, 1994*)*. Illness perceptions are also increasingly being applied to the area of genetic investigation to examine common understandings of the meaning of genetic tests (Sneeuw et al, 1999) and their implication on risk perceptions (Stein and Jessop, 1990) and health behaviour (Lewis **et** al, 1989).

Research is also developing in the area of mental illness and some important findings are beginning to emerge. In this field, the focus has primarily been given to schizophrenia. As in physical illnesses, cognitive manifestations of mental illness are associated with anxiety and depression in schizophrenia patients and in individuals with non-affective psychotic disorder (Fekkes et al, 2000, Gemke & Bonsel, 1996; Grootendorst et al, 1997).

Caregivers of patients with schizophrenia relate their illness perceptions to emotional and behavioral responses to the individual living with the illness and relatives normally live with distress. Recent studies on illness perception have demonstrated the relationship between illness perceptions with behavioral and emotional outcomes of illness

2.7 Chronic Disease Burden, Prevalence, Morbidity and Mortality

Chronic diseases have been in existence since the 1817's in Ghana with cancer of the liver being recorded. In the 1920Ss, cases of stroke were presented and treated at Korle-Bu hospital in the (Pobee, 2006). Between the 1920s and the 1960s data recorded from Korle-Bu hospital showed a continuous of stroke and cardiovascular diseases (Pobee 2006).Studies conducted in hospitals and communities since 1950s highlighted important information on the prevalence and mortality patterns in diabetes, sickle cell, cancers and hypertension.

Chronic non-communicable diseases (NCDs) especially hypertension and CVDs account for a high magnitude of the NCD burden as well as being the major causes of disability and death in

Ghana. The urban and rural hypertension prevalence is 32.3% and 27% respectively (Agyemang et al, 2006 whilst HIV prevalence is 1.8%. Some of the major risk factors for NCDs are; poor diets, overweight/obesity, physical inactivity and alcohol over-consumption.

Evidence-based research shows the role of urban poverty in Sub-Saharan African is faced with barriers to health-promoting behaviours, regardless of the country (Greif et al, 2011). Less endowed communities experience health challenges at several levels starting from "the person's beliefs about health and disease, and actual behaviour, to presentation, screening, risk assessment, negotiation, participation, programme persistence and treatment adherence" (Capewell & Graham, 2010). The attainment of the goals of Universal Health Coverage (UHC).is being undermined by the already overburdened health infrastructure

Research findings shows that there is significant unmet need for the prevention, treatment and care of NCDs. Ghana's healthcare system is burdened with fighting infections and chronic diseases at the same time. These leads to health professionals being poorly trained in NCD diagnosis and management and therefore lack appropriate knowledge and skills (Agyemang et al, 2012; de-Graft Aikins et al, 2010). Ghana's health facilities lack the requisite equipment for diagnosis, monitoring and treatment. Medicines are sometimes expensive or unavailable. There upsurge of traditional medicine practice and faith healing systems offering unregulated chronic disease care to both urban and rural communities (de-Graft Aikins et al, 2010).There is poor patient knowledge of NCDs. Community-based prevalence surveys conducted consistently show that up to 70% of individuals living with hypertension or diabetes do not know they have these conditions (Bosu, 2012). This leads to late reporting's at medical facilities, healer-shopping becoming common (between biomedicine, ethno-medicine and faith healing) and poor self-care.

The morbidity and mortality rates of NCDs and CDs are implicated by multiple factors. The proportion of mortalities related to hypertension and its accompanying complication such as stroke at the Korle-Bu Teaching Hospital in Accra, is around 15% and most of the CVD deaths occur in the productive age group between 40 and 60 years (autopsy series, 1990 – 2000; Sanuade et al, 2014).

Research shows that well-to-do communities encounter higher risk of chronic diseases whilst the less endowed communities have a co-morbid of infectious and chronic diseases. Poverty plays a significant role in NCD risk, morbidity and mortality in Ghana (Agyei-Mensah et al, 2010). Ghana is experiencing a ‘protracted polarized’ health transition with two key elements. First, populations have lived with a protracted co-existence of infectious and chronic diseases over the last few decades. Second, the double burden of disease is spread across socio-economic status. Less endowed communities are prone to developing complications and die prematurely from their conditions due to inaccessibility to medical care and their daily constant contact with health disabling environments.

Specific studies using the generic CDC's HRQoL-4 measures have shown that having diabetes is associated with poor physical health (Campbell et al, 2011).

Cross-sectional studies using the ADDQoL have also shown that patients with diabetes have poor QoL (Collin et al, 2009), Sundaram et al, (2009), especially those that are obese , those with type 1 diabetes , those using insulin and those with diabetes related complications .

A research suggested that using both generic and disease-specific instruments provides a more holistic assessment of HRQoL in patients with diabetes (Rubin & Peyrot, 1999).

The QOL of people with diabetes is associated with firstly, demographic characteristics such as age, sex, education, and ethnicity, secondly, disease-specific attitudes including diabetes self-efficacy, locus of control, and social support, lastly, disease-specific medical factors, including type and duration of diabetes, treatment regimen, level of glycemic control, and presence of complications (Rubin & Peyrot, 1999). Apart from these factors, potential predictors commonly associated with the complex health status of elderly individuals (Inouye et al (2007), such as chronic conditions and geriatric syndromes, should be considered in any exploration of the impact of diabetes on QOL in elderly populations.

During the same period (1950s to present) major causes of death have been changed from solely communicable diseases to a combination of communicable and chronic non-communicable diseases. In Accra, cardiovascular diseases increased from being the seventh and tenth cause of death in 1953 and 1966 respectively, to becoming the number one cause of death in 1991 and 2001 (Agyei-Mensah, 2004). By the year 2003, stroke, hypertension, diabetes and cancer had become one of the top ten causes of death in at least each of the regional health facilities.

2.8 Living with chronic illness

Parsons took a unique approach by describing chronic illness as undesirable state couple with restrictions and limitations. (Parsons, 1951). Furthermore, Frank (1997, p 132) came to an emphatic conclusion that the Parsonian direction changes the ill person into the patient who becomes a “suspicious character”. The physician, according to Frank, is expected to treat the patient without being part in the patient’s withdrawal into sickness”. Frank (1997),

Freidson (1970), Zola (1973) and Mishler (1984) among others refuted the Parsonian view and questioned professional dominance and instead promote viewing the patient as key to the process of illness. Nowadays many researchers argue in the same way (Kleinman, 1988; Bury, 1991; Charmaz, 1991; Morse, 1997; Toombs, 1995) and seek to move the emphasis from being a passive patient to a person who takes action. The physician instead of regulating and limiting illness, he should be seen as more supportive in the patient's acceptance of illness (Anderson & Funnell, 2000; Frank, 1997; Paterson, 2001a).

Frank (1997, p 136) also suggested that focus should be shifted from the challenges of illness to the successes of being ill, where people can find innovative ways to live with illness.

Charmaz (1991, p 7) also proposes that chronic illness may even make the individual to miss daily activities, making people to see the concept of time in different forms. According to Charmaz, "chronic illness often brings out vital lessons about living".

Many researchers have described living with chronic illness as a big task, including Michael (1996) and have to have integrated these into their lives. Patients are usually *being confronted with losses*, which imply not functioning as well as before, and being confronted with changed likeness with others; as well as mood swings, which term describes a mix of frustration, guilt, anger and fear; and *changed routines* which brings about identity conflicts related to meeting the demands. Finally, *control over an altered life situation*, thereby calling for support, seeking knowledge about the disease, fighting against or striving to cope with the demands and making the illness meaningful, helps people to integrate the disease (Michael, 1996).

Paterson, (2001) in a meta-synthesis of 292 qualitative research has looked at chronic illness in a concept called “shifting perspectives model of chronic illness” which describes the phenomenon as either illness or wellness. The research also looks at the individual perception about living with chronic illness and how the person reacts to the symptoms the exhibit and encourages practitioners to support persons with either perspective. In contrary to previous researchers who have described living with chronic illness as a process in determined direction, with a calculated end point, Paterson has found that living with chronic illness is a continuum where people battles with the world making them able to make sense out the situation and the world the live in.

According to Paterson (2001b), with the *illness-in-the-foreground perspective* newly diagnosed people are usually overpowered by the disease, but can also be applied a mechanism of protecting and maintaining the integrity of the individual. The perspective emphasis sickness and suffering including loss and burden and also trigger the individual to deal with the illness by acquiring knowledge on the disease , meditate on it and finally comes to terms with it.

By contrast, a *wellness-in-the-foreground perspective* focuses on the psycho-social and spiritual aspects of life rather than on the diseased body, which is being put aside. Benefits of adopting a wellness-in-the-foreground perspective may include being allowed to take control of the effects of the disease, and remodel himself into a master of his own destiny (Paterson, 2001).

Reviews by Hagger and Orbell, (2003) adopting Leventhal et al, (1980) Commons Sense Model (CSM) of illness representation discovered the relationship between illness cognitions, coping and outcome, e.g. perceptions of strong illness correlated significantly with use of coping strategies of avoidance and emotion expressions. Perceived controllability of the illness was associated with cognitive reassessment, expressing emotions and problem-directed coping strategies. Illness perceived as highly symptomatic, with a chronic time line and serious consequences, is correlated with avoidance and expressing emotional coping strategies. Finally, the perception that illness is curable/controllable is positively related to psychological well-being, social functioning and vitality, but negatively related to psychological distress and the disease state (Hagger & Orbell, 2003).

There are several epidemiological studies than those compared with chronic diseases expedience. There is evidence of work on experiences of diabetes, cancers, sickle cell disease and childhood chronic diseases that built a gloomy picture of the enormous challenges of living life lost per 1000 persons per year, researchers found 17,500 days of healthy life was lost through sickle cell disease, 10, 400 days to cardiovascular disease and 5,100 days to hypertension (Bonsu, 2007). These conditions bring along huge economic challenges making treating of chronic diseases in Ghana is expensive. Without health insurance, managing a condition such as diabetes can cost more than the average individual wages. The burden on the individual and family with chronic disease on treatment and upkeep is so huge that this can even influence the future treatment options. A rural-urban study of diabetes experiences showed that many rural inhabitants who are poor depend on close relations for financial support (de-Graft Aikins, 2005).

This reliance on family members who themselves were financially burdened leads to family tensions and frictions, which in some cases led to family members being abandoned and sometimes social isolation of the victim. Some of these victims end up with healer-shopping within the faith healing systems and traditional medical practice because of the expensive nature of the biomedical treatment.

Reports suggest that some women living with diabetes and cancer are abandoned by their partners because of stigma (Daily Graphic, 2007; de-Graft Aikins, 2006). People living in rural areas with uncontrolled diabetes and also with rapid and extreme weight loss face the risk of, or experience, HIV/AIDS-related stigma (de-Graft Aikins, 2006).

Researchers who have focused their studies on stigma reports that the multiple burdens evoked by stigma constitute a human rights problem that requires rights-based interventions (Campbell & Deacon, 2006, Deacon, et al 2005).

Studies have shown that, the QOL of an individual is affected when the HIV infection (Bourgoyne & Saunders, 2001, Costa et al, 2003). Socio-demographic factors such employment status, age, gender, income, education, HIV stage, severity of HIV infection, and physical as well as mental health affects the QOL of PLHIVs (Cleary et al 1993, Cowdery & Pesa, 2002).

Also, QOL is useful in determining the appropriateness of treatment and interventions like dietary interventions (Echeverria et al, 1999).

An international literature has reported that several factors associated with better QoL among HIV-infected patients and HIV impac has been categorized into four major domains; Socio-demographic characteristics such as male gender (Mannheimer et al, 2005) younger age, (Perez et al 2005) higher socioeconomic status and employment (Swindells et al, 1999) have been linked with improvement in QoL.

Caring for patients with mental illness is considered a very daunting task and calls for home based and community care for such people within the family setting. The changes seen in the patient in terms of behavior and personality can be very discomforting to close family members and key caregivers (Chaturvedi et al, 2006). The family members find it difficult to come into terms with the emotional and personalities break down of their relative. The distress is a function of various factors such as perception, knowledge, and attitude toward the mental illnesses.

Freeman and Simmons (1963) conducted studies which suggested that severe mental symptoms by patient usually frustrate family members because they immediately think about going back to the hospital for another admission. A greater percentage of distressing symptoms observed by (Creer and Wing, 1975) were internal distress and family burden: Physical, emotional and financial, social withdrawal and other negative symptoms.

A study was done by Boye et al, (2001) which looked at the distress relatives endure in relation to the patients' symptoms and behaviors' but there wasn't any relationship established.

Schizophrenia patients have positive and negative symptoms leading to high levels of emotional distress and burden in schizophrenia caregivers (Ukpong, 2006)

2.9 Defining the concept of quality of life

There is yet the opportunity to get an acceptable definition of the concept of QoL (Clark 2004, Bowling 2005, Holmes 2005, Moons et al. 2006, Priebe & Fakhoury 2008), although the term has been in use since the 1960s (Haas 1999). The dilemma has been addressed through the historical development of the concept by many disciplines with each of them having their own differing perspectives (Holmes 2005, Cummins & Lau 2006). Generally, QoL is seen as a multidimensional concept and only understood by the patient alone (WHOQOL Group 1993, Harrison et al. 1996, Haas 1999, Bowling 2003, Moons et al. 2006), which may change over time. The concept has also been defined as having individualized and easily assessed components (Haas 1999, Bowling 2003). The individualized components directly address life experiences (Murphy & Murphy 2006). Thus, the concepts, for example, of happiness, well-being, and satisfaction are terms which are closely connected to QoL (Megens & van Meijel 2006, Murphy & Murphy 2006). The easily assessed components address the situations that have an effect on these experiences (Murphy & Murphy 2006). These components refer to social functioning and living conditions, such as education, employment, finance, and housing and leisure activities. (Barry & Zissi, 1997, Haas 1999, Bowling, 2005.)

As an individualized experience (WHOQOL Group 1995, Harrison et al. 1996, Haas 1999, Bowling 2003, Moons et al. 2006) QoL is based on the belief that each individual has their own definition of QoL (Browne et al. 1997, Fayers & Machin , 2007).

However, research findings have focused on people and their QoL in terms of being psychologically sound, emotionally stable, having good physical and mental health and the physical ability to do the things they want to do, having good relationships with friends and family, participating in social activities and recreation, living in a safe neighborhood with good facilities and services, having enough money and being independent" (Bowling 2005, p. 9).

A study conducted by (Angermeyer et al. 2001) on patients with schizophrenia (n=565) were asked to define QoL, the most common things mentioned were work, health, leisure activities, social contacts, joy of life, family, financial situation, friends, accommodation and independence.

A more convenient term, health-related quality of life (HRQoL), explains the effects of illness on well-being (Danovitch & Endicott 2008). Health, which was defined by the World Health Organization over 60 years ago, as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO 2010), is one aspect of overall QoL (Bowling 2005, Moons et al. 2006). Based on this definition of health, the World Health Organization has defined QoL in the context of health as "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns" (WHOQOL Group 1993, p. 153).

The concepts QoL and HRQoL are used as extensively in health care research. However, it has been argued that focusing on HRQoL may undermine the impact of non-medical factors (Moons et al. 2006).

Multidimensionality (Padilla et al. 1992) has been used in nursing literature as against the definitions of QoL from other disciplines The nursing theorist Peplau (1991), who has been the mother of psychiatric nursing (Howk 2002), has defined QoL as an all-inclusive topic which includes virtually all aspects of existence. She went further to explain that QoL "is primarily a personal perception that individuals have after they sense, observe or inner recognition about their experiences. It is not just about experience but could be an opinion or decision that gives the overall situation, events and a current view about a part or whole life of a person within a given period of time. Thus quality of life is time-related and situation-dependent." (Peplau 1994, p.10.)

Meeberg (1993) also stated in a literature review, that the cardinal characteristics of QoL are: (a) "a feeling of satisfaction with one's life in general", (b) "the mental capacity to evaluate one's own life as satisfactory or otherwise", (c) "an acceptable state of physical, mental, social and emotional health as determined by the individual referred to", and (d) "an objective assessment by another that the person's living conditions are adequate and not life-threatening".

Researchers have shown that surprisingly satisfactory results pertaining to schizophrenia might be as a result of reduction in the expectations of the patients (Carr et al. 2003, Hofer et al. 2004, Becker et al. 2005); and by virtue of the process of human adaptation (Becker et al. 2005). Further researches shows that patients with low perception of their illness, like patients with schizophrenia (Lincoln et al. 2007), report higher QoL indicating that patients with higher insight are aware of their restrictions more clearly (Karow et al. 2008).

More research findings have shown that people with schizophrenia with lower scores in QoL can be related to the psychological domain of QoL. The psychological domain encompasses various psychiatric symptoms, such as anxiety, depression, and psychosis (Bengtsson-Tops & Hansson 1999, Bechdolf et al. 2003, Nørholm & Bech 2006) and the undesired effects of medication (Reine et al. 2003, Hofer et al. 2004). Moreover, low self-efficacy (Bechdolf et al. 2003), self-esteem (Hansson et al. 1999, Hansson et al. 2003), and perceived stigma (Graf et al. 2004), as well as negative coping strategies (Bechdolf et al. 2003), poor problem-solving ability (Caron et al. 2005), and a negative attitude toward antipsychotic medication (Hofer et al. 2004) are major indicators of the psychological domain of QoL, which may impair QoL of patients with schizophrenia.

Also, low scores of QoL among patients with schizophrenia can be synonymous with the physical domain of QoL as a weakened physical state (Hansson et al. 1999, Salokangas et al. 2006).Furthermore; impaired QoL is also related to the level of independence. Patients who have problems in psychosocial functioning (Salokangas et al. 2006), high level of unachieved needs (Fahy et al. 1999, Hansson et al. 2003, Eack et al. 2007) and low rate of performing daily activities (Marwaha et al, 2008) have been shown to suffer from impaired QoL. Moreover being admitted to a mental health hospital (Gråwe & Løvaas 1994, Kaiser et al. 1997), many previous admissions to psychiatric hospitals (Chan & Yu 2004) and alcohol misuse of these patients is related to impaired QoL (Thornicroft et al. 2004, Marwaha et al. 2008, Rocca, 2009).

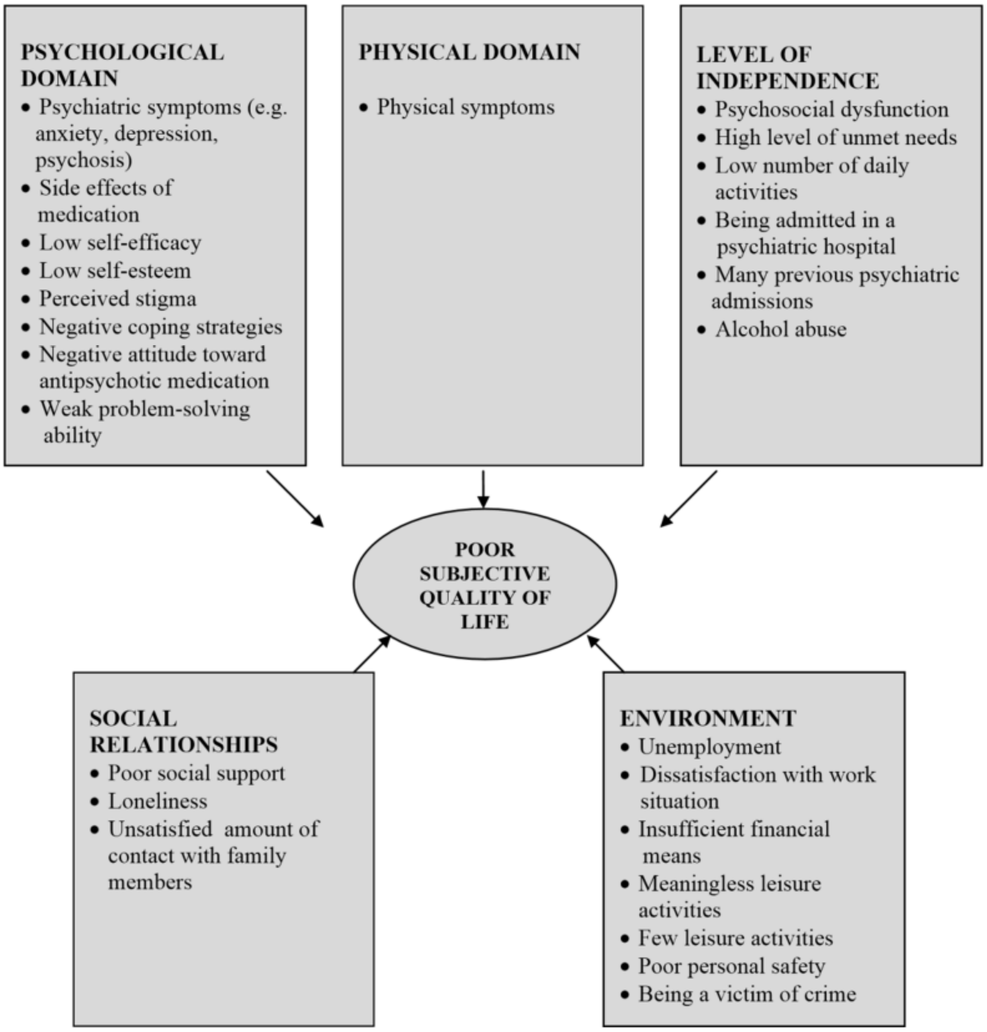
In other studies, social relationships,such as poor social support in patients with schizophrenia may also account for impaired QoL (Koivumaa-Honkanen et al. 1999, Bechdolf et al. 2003, Caron et al, 2005, Eack et al. 2007), loneliness (Hansson et al. 1999, Hansson et al. 2003, Thornicroft et al. 2004, Salokangas et al. 2006), and isolation from family members (Thornicroft et al. 2004, Marwaha et al. 2008) may all lead to impaired QoL

Finally, matters related to patients' environment may impair QoL in that unemployment or unsatisfied job situation (Chan & Yu 2004, Thornicroft et al. 2004, Bengtsson-Tops & Hansson 1999, Hansson et al. 1999) and insufficient salaries of wages (Bengtsson-Tops & Hansson 1999, Heider et al. 2007) are indicative of impaired QoL. Moreover, impaired QoL is equivalent with worthlessness and irregular leisure activities (Hansson et al. 1999, Thornicroft et al. 2004), poor personal safety levels (Hansson et al. 1999), and being a victim of wrong doing (Marwaha et al. 2008).

It is noteworthy that in the literature of predictors related to QoL are somewhat in different perspectives contradictory; with some studies have reported negative influence on QoL others have not found any.

A summary of the above literature of potential factors related to impair QoL in patients with schizophrenia is presented in Figure 2 grouped according to the WHOQOL Group's (1993) conception of QoL domains.

Figure 4.1: Factors potentially impairing QoL in patients with schizophrenia



QoL is a construct that includes health and functioning, socioeconomic status, psychological, emotional and spiritual aspects, and family (Ferrans, 1990). Ferrell, (1996) confirmed the influence of such multidimensional aspects on the QoL for breast cancer survivors. Wyatt & Friedman (1996) also came out with concerns related to QoL in those with chronic physical illness, and suggested that considering multidimensional aspects of QoL for them is essential. Although some scholars have different point of views regarding the various dimensions of QoL, most researchers generally agree that QoL is multidisciplinary, subjective, and associated to a state of physical, psychological, social, spiritual well-being (Zebrack, 2000). However, QoL for caregivers includes more aspects such as burden and family functioning (Cameron et al, 2002). Further, some researchers use QoL in terms of life satisfaction, adaptation, health, and distress (Hally & Bartolucci ,1987, Wallhagen, 1992, Boyle et al,2000, Cameron et al,2002, Pot et al ,2000). Such holistic or comprehensive consideration has led to an awareness of QoL as a broader and more appropriate concept for determining how caregiving affects family members (Canam & Acorn, 1999).

According to QoL (Karen et al., 2008) ,QoL is an important indicator of health and well-being, which determines the effectiveness of treatment, plan the priority areas for resources distribution, and help in policy developments. Since chronic disease is not palliative, the main aim is to improve the well-being of patients and prolong their lives without symptoms; hence QoL is used to appraise the outcome of treatment given. QoL shows what the patient wants ,gives an idea of what other symptoms the patient presents and the kind of problems that the patient faces (Fayers & Machin, 2007).

The activities that caregivers usually assist patient or carry out for patient include house-cleaning, grocery shopping, cooking, administering medicine, bathing, paying bills, using the toilet, dressing, eating, etc. Family caregivers or informal caregivers are those who are not given salaries or wages for their care-giving services rendered. The most common types of care-giving relationships in the world and for that matter Ghana include: providing care to adults in one’s family, such as grandparents, uncles, aunts, and siblings; spouses providing care to a sick husband or wife; middle-aged parents providing care to their disabled children who may be adult; providing care to a friend or neighbor, and children providing care to a disabled parent or elderly and sick grandparent. Care-giving is a job without clearly defined aims or goals. Family caregivers usually do not have any formal training or knowledge in rendering quality services, sometimes they usually even ignore their own health whilst taking care of the patient (Ansari & Qureshi, 2013).

Care-giving is a demanding and daunting task which places great life stress on the caregivers.

A Study to understand Prognosis and Preferences for outcomes and Risks of treatment reported that one fifth of all family members of severely ill patients had to abandon work or make another major life change in order to care for their family members. Almost one third reported the loss of all their family income reserves and 29% reported loss of major source of family income (Imran et al, 2010)

It is well known fact from studies that care-giving burdens can lead to caregivers with a relative suffering from mental illness experiencing poor quality of life (Zahid & Ohaeri, 2010)

QoL is the perceived quality of an individual's daily life, that is, an appraisal of their well-being or lack thereof. This includes all emotional, social and physical aspects of the individual's life (Bottomley & Andrew, 2002)

In Pakistani setup, just as in Ghana, family caregivers are regarded as the pillar of the healthcare system. The closest relatives such as, patient spouses, parents or siblings are responsible for providing physical and emotional support for the mentally ill patients for long periods ranging from months to years. Due to this long period of enormous responsibility the caregivers turn to be affected mentally, physically as well as quality of life (Bottomley & Andrew, 2002).

Quality of life is one's personal satisfaction (or dissatisfaction) with the cultural or intellectual conditions under which you live (as distinct from material comfort) and also quality of life is the general wellbeing of individuals and societies (Khalid et al, 2008)

Caregivers face numerous problems, challenges and issues which affect their psychological wellbeing. The emotional and physical stress that they carry can take many forms like frustration, depression, fatigue, anger, guilt, loneliness, etc. According to Women's health.gov (a project of the United States Department of Health and Human Services Office on Women's Health), care-giving stress affects women more than men.

Approximately, 75 percent cases of emotional, physical, or financial stress have been reported by women. Although the concepts of caregiver burden and strain have not been well defined in the studies, they suggest a direct measure of the duty of caring. This is directly opposite to the concept of QoL which appraises a far broader spectrum relating to an individual's overall wellbeing (Brody & Jane, 2012)

Depending on the clinical scenario, both agreeing and disagreeing perspectives in couples have been related to better patient adjustment (Kaptein et al, 2007). Other studies have focused more on the relevance of relatives' illness perceptions to the experience of the relatives.

2.10 Summary of Literature Review

The literature review has highlighted the importance of understanding illness perceptions in primary care patients. It also demonstrated strong associations between illness perceptions and the later use of healthcare. The literature suggests that discussions with patients about their thoughts and ideas about their illness could help clear up misconceptions and reduce the risk of the health problem developing into a later chronic condition.

The review also shows that the diagnosis of any chronic illness/disease confronts individuals with a collection of tasks necessary for both physical and psychological adjustment. It was found that relatives of patients with chronic diseases/illness perceptions are related to emotional and behavioral responses to the individual with the illness and distress in the relatives who care for these patients.

The literature review shows that most of the research in Ghana has focused on the prevalence of chronic diseases and cardiovascular diseases (CVDs). The literature review shows that there is significant unmet need for the prevention, treatment and care of chronic needs. The studies in Ghana have not shown the relationship or impact of chronic diseases on the quality of life of the victims and their relatives.

Literature on the impact of chronic diseases on the QoL of the victims and their caregivers is limited and very scanty. This study seeks to add to the literature that explores the QoL of people living with chronic diseases in the Bolgatanga Regional Hospital and Ghana as a whole.

The literature review concludes that most illness perception studies have been designed to demonstrate the associations of illness perceptions with behavioral and emotional outcomes of illness.

CHAPTER THREE

METHODOLOGY

3.0 Introduction

The methodology that was used in conducting the study is presented in this chapter. The sections under this chapter include the study design, description of the study area, study population, sample size determination and sampling procedure, data collection, dependent and independent variables, data processing and analysis and ethical considerations

3.1 Description of study setting

The Regional hospital, Bolgatanga was established in 1946 to serve the minority white population of the then Gold Coast .It is a Regional Referral Hospital and training center for doctors, laboratory personnel, nurses and midwives.

It has accreditation to train housemen medical officers in surgery and O & G and has a total Bed complement of 226. It has total staff strength of about 415 on the payroll but engages the services of 96 casual workers, bringing the total workforce to about 511.

As a Regional Referral Hospital, it has a catchment area population of about 1,084,656.

The main economic activity of the people in the region is agriculture involving crop production and livestock farming. Some of the crops cultivated are maize, sorghum, millet, groundnut, cowpea, soya beans and rice. Other economic activities undertaken in the region are small- scale agro-based procedures such as Shea butter processing, rice milling, groundnut oil extraction Pottery, basket weaving and soap making. Fishing and lives stocks are considered as supplementary activities to crop farming. Large scale fishing is carried out at in Tono dam in Navrongo and Vea dam also in Bolga.

There are different ethnic groups in the Munucipality. The major groups, however, are Gurunes, Kusasis, Kassenas, Bulisas and Manprusis. Others include Ewes, Akans and Biisas.

There are three major religious groups in the Region. These are as follows: Islam constitutes about 24.3% Christianity 66.7% while traditional religion also constitutes about 8.3%.

There has been a steady rise of chronic diseases in the region especially in the Upper East Regional Hospital .According to the end of year performance of the hospital for three years running,

DISEASE	YEAR 2013	YEAR 2014	YEAR 2015	TOTAL
DIABETES	444	669	785	1898
STROKE	58	72	134	264
HIV/AIDS	267	328	432	1027
SCHIZOPHRENIA	437	524	645	1606

3.2 Study Design

A cross-sectional design was adopted for this study and respondents across various departments/disease units were involved (HIV/AIDS, Diabetes, Stroke, and Mental Health), sexes, ages, religion, and educational levels were used in examining the respondents' (client and caregiver) quality of Life and illness perception. This is a non-experimental study in which data was collected from 4thMay 2015 to 17thJuly, 2015.

3.3 Sample size

Participants in this study were 144 pair of patients and their caregivers (CD patients and their partners) who were recruited from the outpatient clinics of the Departments of the Regional Hospital. Chronic Diseases(CD) patients from the facility were selected if they had received a clinical diagnosis of CD at least 1 year prior to commencement of the study, and they were capable (mentally, emotionally, and physically) of participating in an interview lasting approximately 1hour. The selected patients and their caregivers were invited during clinic days to participate. A total of 288 respondents (married or living together) were identified. Patients and their caregivers were interviewed separately at the clinics by the trained research assistants.

The sample size for the study was calculated using Cochrane sample size calculation formula below: (Cochrane, G.C. 1989)

$$n = \frac{Z^2\, p(1-p)}{e^2}$$

$$where:$$

$$n \ = \ the\ sample\ size$$

$$Z = \ the\ confidence\ level\ set\ at\ 95\% = 1.96$$

$$p = \ the\ proportion\ of\ chronic\ diseases\ in\ Ghana \ = \ 12\%$$

$$e = \ is\ the\ desire\ level\ of\ precision \ = \ 0.05$$

$$n = \frac{1.96\ X\ 1.96X\ 0.12(1 - 0.12)^2}{0.05^2}$$

$$= \frac{1.96^2(0.12)(0.77)}{0.0025}$$

$$= \frac{(3.8416)(0.0924)}{0.0025}$$

$$= 142$$

In order to take care of non-response rate, 2%of the sample size was added.

$$2/100 \ \times \ 142 \ = \ 2.84$$

$$2 \ + \ 142 \ = \ 144$$

Hence the sample size for the study = 144 participants

3.4 **Study Population**

The Population for this study is all individuals with chronic illnesses (specifically, HIV/AIDS, diabetes, stroke, mental illness) in the Upper East Region who attended the regional hospital various clinics for services.

3.5 Study Variables

Dependent Variables

The dependent variables of the study are;

- Illness perception of Patients and family Caregivers
- Quality of life of Patients and Caregivers

- **Independent variables of the study are**
- The various disease conditions/ Clinics
- Age of respondents
- Sex
- Tribal distribution
- Marital status
- Parity
- Religion

3.5 Sampling Procedures

The convenience sampling procedure was used to select the respondents for this study as this method involves using samples who are readily available (Leedy & Ormrod, 2010). That is, respondents who were available and willing to participate in the study were used.

Patients were selected according to specific inclusion and exclusion criteria. The inclusion criteria for patients were: patients, who were over 10 years of age, diagnosed with HIV/AIDS, Stroke, Diabetes and Schizophrenia and had been on regular routine visits as prescribed at the regional hospital for more than three months. Exclusion criteria were patients who were too sick to give information, those without caregivers and patients and caregivers who refuse to give consent.

3.6 Measurement of outcome variables

3.6.1 Demographics

Pertinent demographic and clinical information including age, sex, employment, educational, and marital status were gathered using a self-designed questionnaire labelled demographical characteristics.

3.6.2 Quality of Life

QOL was measured with the World Health Organization Quality of life questionnaire (WHO QOL-BREF) instrument. WHO QOL-BREF is a shortened version of the WHO QOL instrument consisting of a 26 item questionnaire that is comparable across different languages and cultures. WHO QOL-BREF has been well validated for measuring quality of life in people living with chronic diseases across different settings and has been extensively used by similar studies elsewhere. It has a Cronbach's alpha of 0.70 (Najafi et al, 2009). The questionnaire gathered data on the four domains, Physical, Psychological, and Social as well as Environmental. This information focused on the client's rating of his or her views on quality of life related to the four domains.

In measuring the illness perception and quality of life of respondents, the Illness Perception questionnaire (IPQ-R) and WHOQOL-BREF questionnaire were used to respectively collect data. Both questionnaires are standard tools where respondents answer likert questions, which are then scored under a likert scale. In the likert scale, each respondent is scored based on their response to a number of questions which can then be scaled to measure the variable of interest;

in this case, the variables of interest are illness perception and quality of life, each corresponding to its scaled questionnaire. Kindly refer to appendix for both questionnaires. Both patients and caregivers were administered each of the questionnaire.

Both questionnaires have a number of questions which a participant responds to. In scoring and scaling, each questionnaire is divided into domains where each response score feeds into a particular domain. Each domain therefore comprises a number of scored and scaled responses coming together to represent a particular implication.

3.6.3 The Illness Perception Questionnaire

This questionnaire by Helder et al, 2000, was used to assess the illness perceptions of patients and those of their partners/ carers'. The IPQ consists of the following five subscales: "Identity", "Timeline", "Cause", "Consequences", and "Cure/Control". Patients are asked to rate whether or not they have experienced each symptom since their illness began, and if they believe the symptom to be specifically related to their illness (yes or no). Caregivers completed a caregiver version of the Brief IPQ developed and utilized in prior study (Broadbent et al, 2009) with items phrased to reflect the caregivers' perception of the patient's chronic disease. Partners/Caregivers were asked whether or not their partner (the patient) had experienced each symptom since onset of their illness, and to report if they believed the symptom to be specifically related to their partners'/Patient's illness (yes or no). The summed yes-rated items on the second questions were divided by the number of items to form the illness identity scale, with higher scores indicating a stronger belief that the experienced symptoms are part of the patient's illness. Cronbach's alpha for patients and partners/caregivers was 0.88 and 0.82, respectively. The Illness Perception Questionnaire has 9 domains which include *Identity, Timeline, Consequence, Personal Control, Treatment control, Illness coherence, Time Cyclical, Emotional representation and causes of* *illness*. Responses/items for the Identity domain is scored as yes=1 and no=2, whiles items for the other domains are scored on a scale of 1 to 5 ranging from strongly disagree to strongly agree respectively. Domains of the Quality of Life questionnaire are *Physical health, Psychological, Social relationship and environment*. Each response/item is scored on a scale of 1 to 5.

3.7 Quality Control Measures

Reliability is the degree of consistency that the instrument of procedure demonstrates whatever it is measuring and it does so consistently. The interviewers were trained on how to translate the questionnaire into the local language before work commenced. The questionnaire was pretested in one of the health facilities to ensure clarity and that the respondents will give the right responses before it was administered.

All completed questionnaires were checked on the field by the field supervisor to ensure that all the questionnaires were properly completed.

In order to establish the reliability of the tool the Cronbach's alpha was calculated. This was found to be 0.8622 which is high and closer to 1. This represents a higher internal consistency of the variables or scale.

Training: There was a training session for the research assistants who assisted in the data collection to ensure that valid and reliable data were collected. The training gave the data collectors much insight into the questionnaires and what it sought to achieve.

Pre-testing of questionnaires:

Pre-testing of the tool was done to check clarity of items, ambiguity of the language and feasibility of the tool. Formal permissions were obtained from the concerned authorities.

A pilot study of 20 conveniently selected respondents from Sickle Cell Unit was used to ascertain the consistency or the appropriateness of the various measures used to collect data from the respondents.

The time taken by each respondent to answer the questions varied from 20-30 minutes. The tool was found to be clear feasible and there was no ambiguity in the language

Double entries of data: The quantitative data was entered by two persons after which the two data sets were compared to check inconsistencies in the data.

3.8 Data Processing and Analyses

All 288 participants successfully responded to each questionnaire. Each response was scored based on respective likert scales of the standard questionnaires. Individual respondent's scores were then entered into the Statistical Package for Social Sciences (SPSS), version 21, to generate the group mean of each category of respondents (caregivers and patients). To ascertain any difference in illness perception between caregivers and patients, a t-test was carried out to compare the two group means (caregivers and patients). However, to ascertain any difference in illness perception among the four illness conditions, an ANOVA was carried out to compare the means of each illness group. Where the analysis resulted in a difference in means, a posthoc was further done to specifically explore the differences among the means. The ANOVA (and posthoc if necessary) was also carried out to compare the means of the four illness groups of patients to establish any differences in quality of life. Same was done to also ascertain any difference in quality of life for the caregivers.

Demographic data of respondents were also collected and entered into the SPSS to generate any descriptive statistics. Kindly refer to appendix for questionnaire.

3.9 Ethical Consideration

The proposal for the study was presented to the Medical Director of the Upper East Regional hospital after it was approved by the University as well as the hospital's research team.

A letter of introduction from the Regional Hospital management was taken and given to the heads of the various selected clinics/departments to help seek permission to conduct the study after ethical clearance has been granted. A written consent note was attached to the questionnaire and communicated orally to the participants before the interviews were conducted

This random study was done among individuals who attended the outpatient Anti-Retroviral Therapy (ART) Clinic, Diabetic Clinic, Mental Health Unit (MHU) and the Physiotherapy Department (for Stroke patients) of Regional Hospital, Bolgatanga (RHB), from May -July 2015. The clients and their caregivers were informed about the nature of the study, its importance as well as the benefits of being part of the study. Therefore, available and willing respondents were helped in responding to questionnaire of the study. All ethical protocols (informed consent, anonymity, confidentiality, and debriefing) was adhered to.

CHAPTER FOUR

RESULTS

4.0 Introduction

This chapter presents results of the study. Data from a total of 288 respondents were analyzed. Results were presented based on responses from participants and caregivers and are illustrated in tables and figures. Results were obtained from responses from a single hospital visit. Analysis was done at the univariate, bivariate and multivariate levels.

4.1 Socio-demographic characteristics of the Patients

The demographic characteristics of the patients are presented in Table 4. 1. The total sample size used for the study was two hundred and eighty-eight (288), representing one hundred and forty-four (144) for patients and a hundred and forty-four (144) for patients' caregivers. These constitute 50% for Patients and their caregivers equally. Descriptive statistics for patients revealed that there were 54 (37.5%) from Anti-Retroviral Therapy (ART) clinic, 35 (24.3%) from Mental Health Unit (MHU), 36 (25%) from Diabetes clinic and 19 (13.2%) from the physiotherapy department. Females recruited were 82 (56.9%) whilst males were 62 (43.1%). Furthermore, majority were Christians (66.7%), married (61.8%), with about 3-5 children (38.2%), and 'O/A' level education (40.3%). Other further details about patients used in this study are reported in Table 1.

Patients were asked whether they were currently ill and they responded as follows; 74.31% of them said they were ill of one illness or another and 25.69% said they were not ill at that moment.

The patients were asked to list the illnesses that affect them if any and the following responses were realized.

4.2 Sample Characteristics

Table 4.1 Socio-demographic Characteristics of the Patients

Variable	**N**	**Percentage (%)**
Illness		
HIV/AIDS	54	37.5
SCHIZOPHERENIA	35	24.3
DIABETES	36	25
STROKE	19	13.2
Total	**144**	**100**
Sex		
Males	62	43.1
Females	82	56.9
Total	**144**	**100**
Religion		
Christian	96	66.7
Muslim	35	24.3
Traditionalist	12	8.3
Total	**143**	**99.3**
Marital Status		
Single	26	18.1
Married	89	61.8
Separated	5	3.5
Divorced	4	2.8
Widowed	18	12.5
Total	**142**	**98.6**
Number of Children		
None	29	20.1
1-2	36	25
3-5	55	38.2
More than 5	24	16.7
Total	**144**	**100**
Highest Educational Level		
No formal Education	74	51.4
‘O’/‘A’Level	58	40.3

Undergraduate	4	2.8
Postgraduate	4	2.8
Total	**140**	**97.2**

4.3 Signs, Symptoms and Complaints about the Diseases

From the table 2, 9(6.25%) said they came because of the diabetes, 9(6.25%) also complained of having headaches, 7(4.86%) reported having palsy; weakness of limbs and 5(3.47%) also reported due to HIV/AIDS related symptoms. The rest of the responses can be seen in the table.

Table 4. 2 : Presenting signs and symptoms

Diseases/ Complaints	Frequency	Percent
Diabetes	9	6.25
Headache	9	6.25
BP	1	0.69
HIV/AIDS	5	3.47
Abdominal Upsets	3	2.08
Psychosis	2	1.39
Germs/Viruses	1	0.69
Poor Nutrition	3	2.08
Typhoid	1	0.69
Palsy ; Weakness of Limb(s)	7	4.86
Non-respondents	103	71.53
Total	**144**	**100.0**

4.4 Source of Income of Respondents

From the table 4.3, respondents gave the varied avenues through which people had their daily bread.47 (32.64%) of them get their income from family and friends, 35(24.31%) are through savings, interest and dividends, 15(10.42%) income comes from pensions. The sources of income are shown in table 3;

Table 4.3 : Primary source of income

Sources of income	Frequency	Percent
Savings, interest dividends	35	24.31
Annuity	12	8.33

Pension	15	10.42
Veterans' benefits	13	9.03
Family and Friends	47	32.64
Job/ Salary	10	6.94
Social security	3	2.08
Business	9	6.25
Total	**144**	**100.0**

4.3 Socio-demographic characteristics of the Caregivers

The demographic characteristics of caregivers are presented in Table 4.4. Descriptive statistics revealed that majority of caregivers were currently employed (68.8%). More so, majority of their relatives or neighbours lived with significant others/spouse (39.6%) before the sickness, currently majority lives with significant others/spouse (43.8%) in an apartment or home (95.1%). Other descriptive statistic details are also presented in Table

Table 4.4: Socio-demographic Characteristics of the Caregivers

Variable	**N**	**Percentage (%)**
Clinic/Unit/SELECTED DISEASE		
Anti-Retroviral Therapy (HIV/AIDS)	54	37.5
Mental Health Unit (Schizophrenia)	35	24.3
Diabetic Clinic (Diabetes)	36	25
Physiotherapy (Stroke)	19	13.2
Total	**144**	**100**
Currently Employed		
Yes	99	68.8
No	42	29.9
Total	**141**	**97.9**
Who was your relative/neighbour living with?		
Alone	11	7.6
Friend/Room mate	3	2.1
Children	39	27.1
Parents	29	20.1
Significant Others/Spouse	57	39.6
In school	1	0.7
Total	**140**	**97.2**

Who is your relative/neighbour living with now?		
Alone	4	2.8
Friend/Room mate	4	2.8
Children	**33**	**22.9**
Parents	**40**	**27.8**
Significant Others/Spouse	63	43.8
Total	**144**	**100**
Where is your relative/neighbour living now?		
Apartment/home	137	95.1
Boarding house	2	1.4
Group home or Halfway home	4	2.8
Homeless	1	0.7
Total	**144**	**100**

4.5 Treatment Goals

From table 4.5, 92 (63.89%) of the respondents said good health for their relatives is what the desired, 28(19.45%) wanted their relatives illnesses managed through constant medical care, also 12 (8.33%) wants their relatives to be able to use the affected body part to work, whilst 3(2.08%) wants to see their friends' blood Sugar level controlled and 1(0.69%) needed their relative's stigma to be reduced.

Table 4. 5: Important treatment goals for your relative/friend/neighbor

Treatment Goal 1	Frequency	Percent
Good health	92	63.89
Manage illness by ensuring constant medical care	28	19.45
Good Hygiene	8	5. 56
Reduce stigma	1	0.69
Control sugar level	3	2.08
To be able to use the affected body part(hands, legs etc)	12	8.33
Total	**144**	**100.0**

From the table 4.6, 63 (43.76%) of the caregivers desired that complications should be prevented or controlled for their relatives, whilst 29(20.14%) wants their neighbors to be able to associate with others without stigma, 26 (18.06%) also wants good nutrition and the ability to be able to manage their diet well.

Table 4.6: Important treatment goals for your relative/friend/neighbor

Treatment Goal 2	Frequency	Percent
Nutrition; diet management	26	18.06
Prevent complication/control illness	63	43.76
Associate with others and to avoid stigma	29	20.14
Reduce stigma	5	3. 45
To be able to walk and use hands to work	21	14.59
Total	**144**	**100.0**

The third goal that the caregivers wish for their relatives is that they should be educated on their illnesses, 63(43.75%), also 32(22.22%) wants good nutrition and personal hygiene maintained, 29(20.14%) wants the psychological well-being of their neighbors and to be able to integrate into society. The caregivers also wants their relatives to be able to speak well again, 12(8.33%) and 8(5.56%) of them wants to see their neighbors perform their daily activities.

Figure 4.2 Treatment goals

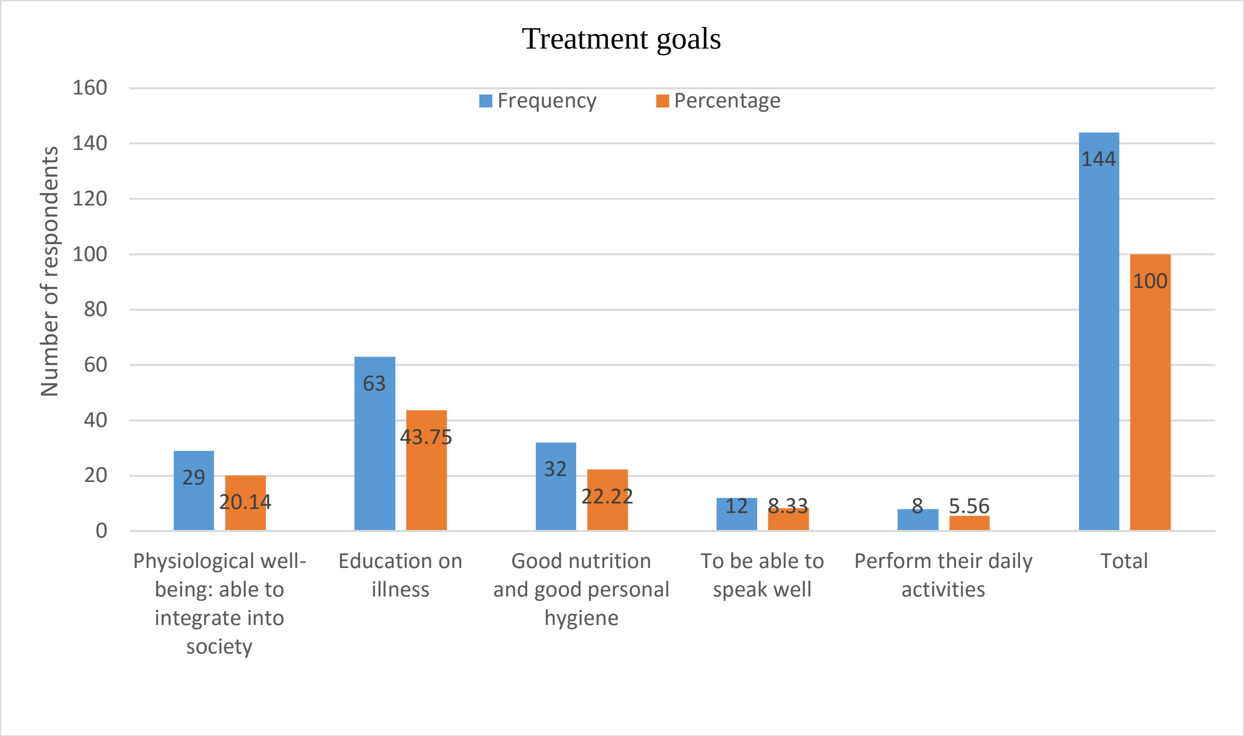
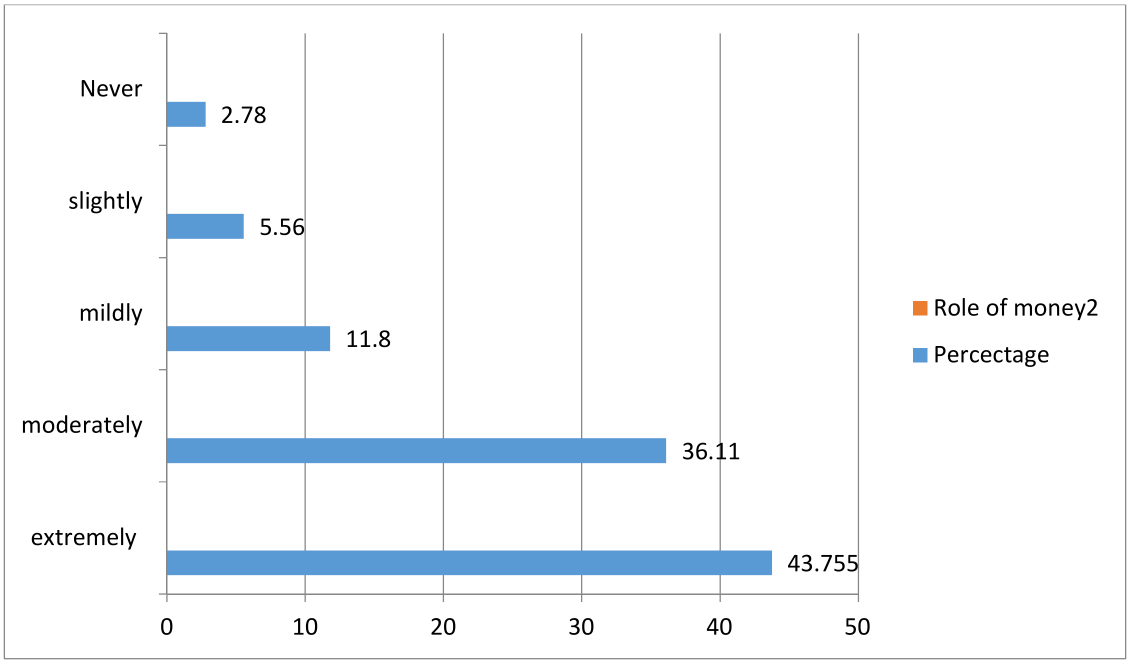


Figure 4.3: Treatment goals

4.6 Role of money on the Quality of life

Figure 4.4 represents the views of the caregivers concerning the role of money on their relatives' quality of life. About 43.75% believe money is extremely important, 36.11% of them think money is moderately important, 11.8% of the caregivers believe it is mildly important, 5.56% thinks it is slightly important and 2.78% sees money not to be important in determining their relative's quality of life.

Figure 4. 3 Role of money



4.7 Role of Work on Occupational Activities

Figure 4.5 shows the views of the respondents on the impact of work, school and other occupational activities on their QOL.88 (61.11%) of them see these factors to be moderately important,24(16.67%) sees them to be extremely important, whilst 19(13.10%) view those factors as mildly important.

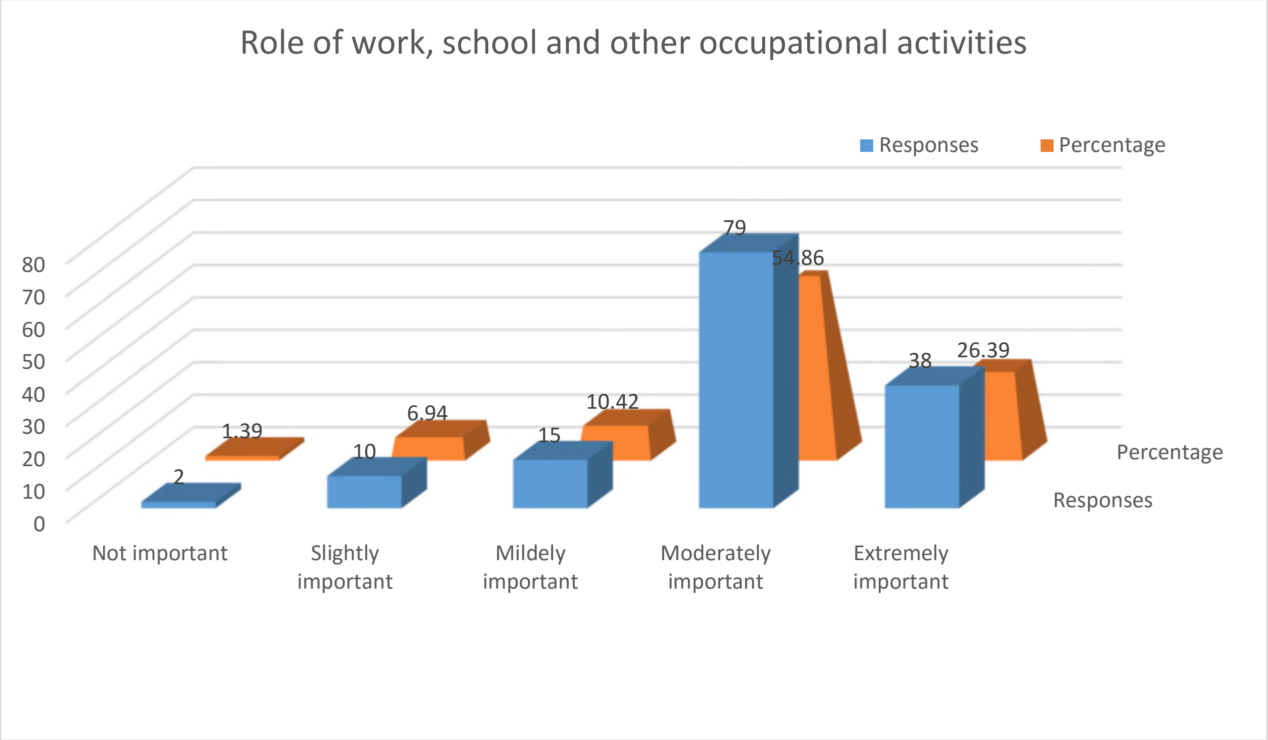


Figure 4.4 Role of work, school and other occupational activities

As to friends, family, people, relative/neighbor's time with patient being a determinant, 38(26.39%) of the respondents believe it was extremely important, 79(54.86%) thinks it was moderately important. The other views can be seen in table 4.7.

Table 4.7: Friends, family, people relative/friend/neighbor's spends time with

Time spent with Friends/Relatives/Neighbors	**Frequency**	**Percent**
Not important	2	1.39
Slightly important	10	6.94
Mildly important	15	10.42
Moderately important	79	54.86
Extremely important	38	26.39

Total	**144**	**100.0**

Mental health according to 72(50%) of the care givers believes it moderately determines the QoL of their relatives. Also 50(31.72%) of them think mental health extremely determines one’s QoL, whereas 16(11.11%) thinks it is mildly important and 6(4.17%) believe it is slightly important.

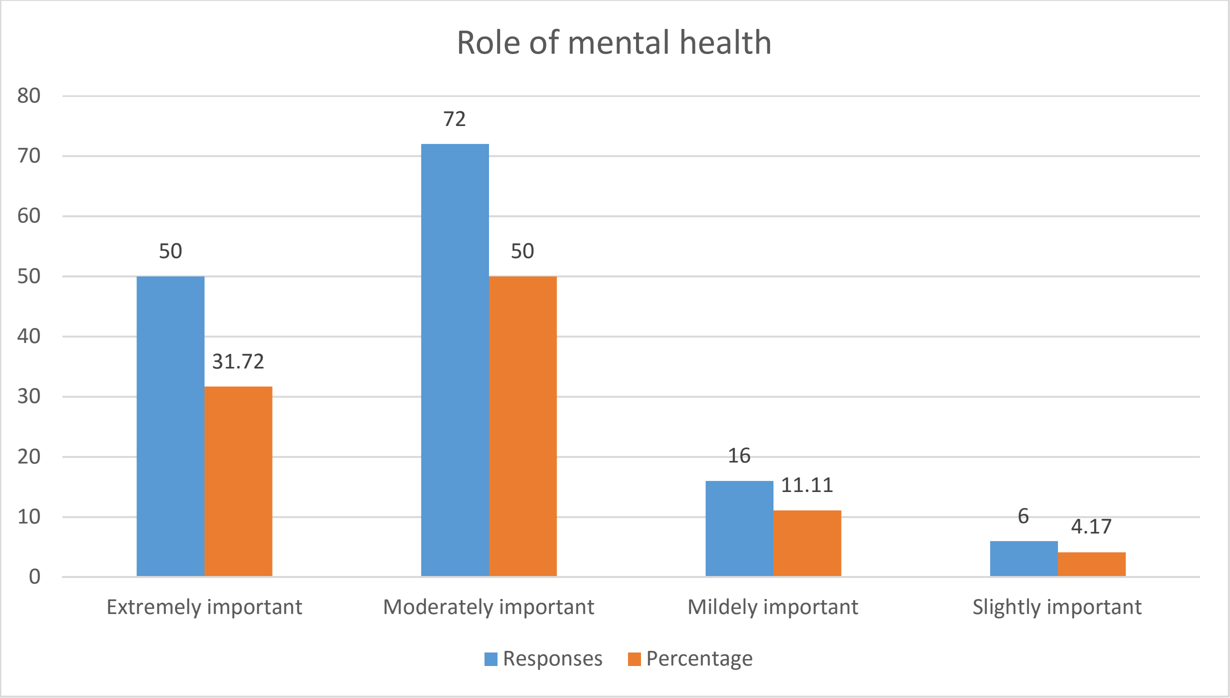


Figure 4.5: Role of mental health

Caregivers were asked as to what they will now want to be done for their neighbors and these were some of the responses;59 (40.975%) of them want drugs to be provided since most of them relied on that, 39(27.08%) of them also wants their relatives to be educated on the importance of reviews and prescriptions,whilst 33(22.92%) of carers wants them to be well and fit well in society and 13(9.03%) of them wants their relatives exercises to be intensified.

Table 4.8: Important needs

Additional care/support	**Frequency**	**Percent**
Provide drugs for them	59	40.97
Educate him/her on importance of review/prescription	39	27.08
For him to fit well in society	33	22.92
Intensify exercise	13	9.03
Total	**144**	**100**

4.9 Objective 1: Differences between patients and caregivers illness perception

According to Table 4.9, caregivers (*M* = 171.50, *SD* = 12.45) had significantly more scores (total) than the patients (*M* = 166.62, *SD* = 15.29) on illness perception [*t* (286) = 2.966, *p* = .003]. At the subscale level, it was found out that there was no significant difference between caregivers view about illness and patients view about illness [*t*(286) = 1.843, *p* = .066]. However, caregivers had significantly more scores (*M* = 46.12, *SD* = 9.70) than the patients (*M* = 43.31, *SD* = 9.52) on possible causes of the illness [*t* (286) = 2.483, *p* = .014]. Therefore, the objective that a significant difference would exist between caregivers and patients on illness perception was supported by the data.

Table 4. 9: Means and Standard deviations of Patients and Caregivers perception on Illness

Respondents	Variables	N	M	SD	*df*	*t*	Sig
Caregivers	Views about illness	144	125.38	7.11	286	1.843	.066
Patients		144	123.32	11.39			
Caregivers	Possible Causes	144	46.12	9.70	286	2.483	.014
Patients		144	43.31	9.52			
Caregivers	**Total**	**144**	**171.50**	**12.45**	**286**	**2.966**	**.003**
Patients		**144**	**166.62**	**15.29**			

Objective 2: Differences in illness perception among the four conditions

Results in Table 4.10 indicated that there are differences between the Means (and Standard Deviations) of patients from the four different conditions. However, these differences were subjected to testing using the inferential statistics, One-Way ANOVA to find out whether a significant difference exists. The results are shown in Table 4. 11.

Table 4.10: Means and Standard deviations of Patients of different Conditions on Illness Perception

Variables	**HIV/AIDS**		**SCHIZOPHRENIA**		**DIABETES**		**STROKE**	
	M	**SD**	**M**	**SD**	**M**	**SD**	**M**	**SD**
Views about illness	129.98	10.74	118.26	14.08	113.47	7.87	120.53	9.60
Possible Causes	40.35	6.53	50.91	11.14	42.00	8.79	40.89	6.92
Total Illness	**167.33**	**14.77**	**169.17**	**20.68**	**155.47**	**10.82**	**161.42**	**11.88**

Perception								

Results revealed that in total, there was a significant difference between the four illness conditions on illness perception [*F* (3, 140) = 14.392, *p* = .000]. At the subscale levels too there was a significant difference between the four conditions on Views about illness [*F* (3, 140) = 4.523, *p* = .005] as well as Possible Causes [*F* (3, 140) = 13.638, *p* = .000]. The Scheffe post hoc test was used to find out the exact differences between the groups. It was revealed that for views about illness, HIV/AIDS patients have more significant scores than Schizophrenia patients. For causes of illness, it was revealed that HIV/AIDS patients have more significant scores than Schizophrenic patients whilst Schizophrenic patients have more significant scores than Diabetes patients. In total, Schizophrenic patients have more significant scores than Diabetes patients. Hence, the objective that different group of patients would have different perception about their illness was supported by the data.

Table 4. 11: Sum of squares and Mean square of Patients of different Conditions on Illness Perception

	Sum of Squares	***Df***	**Mean Square**	***F***	**Sig.**	**Scheffe Post Hoc Comparison**
Views about illness	1616.513	3, 140	538.838	4.523	.005	HIV/AIDS > SCHIZOPHRENIA
Possible Causes	2934.903	3, 140	978.301	13.638	.000	HIV/AIDS > SCHIZOPHRENIA, SCHIZOPHRENIA, > DIABETES

Total Illness Perception	**3274.730**	**3, 140**	**991.577**	**14.392**	**.000**	**SCHIZOPHRENIA, > DIABETES**

Results in Table 4.12 indicated that there are differences between the Means (and Standard Deviations) of patients with chronic conditions from the four different illness conditions. However, these differences were subjected to testing using the inferential statistics, One-Way ANOVA to find out whether a significant difference exists. The results are shown in Table 4.13.

Objective 3: Differences in quality of life of patients

Table 12: Means and Standard deviations (SD), Comparing quality of life of patients suffering from selected chronic diseases

Variables	**HIV/AIDS**			**Schizophrenia**			**Diabetes**			**Stroke**	
	M	**SD**		**M**	**SD**		**M**	**SD**		**M**	**SD**
Physical	24.70	3.89		23.91	2.78		23.14	3.74		22.16	4.25
Psychological	20	3.19		20.37	2.61		19.42	3.30		19.58	3.53
Social	9.43	2.34		9.74	2.36		10.17	1.80		9.68	1.8
Environment	25.28	4.46		25.49	4.96		26.36	3.86		25.95	4.47
Total	**79.41**	**11.92**		**79.51**	**11.32**		**79.08**	**9.97**		**77.37**	**12.39**

Results revealed that in total, there was no significant difference between the four conditions on patients' quality of life (QoL) [*F* (3, 140) = 0.175, *p* = .913]. At the subscale levels too there was no significant difference between the four illness conditions on Physical QoL [*F* (3, 140) = 1.772, *p* = .054], Psychological QOL [*F* (3, 140) = 0.633, *p* = .595], Social QOL [*F*(3, 140) = 0.855, *p* = .466] and Environmental QOL [*F*(3, 140) = 0.473, *p* = .702]. Therefore, the objective that different group of patients would have significantly different quality of life was not supported.

Table 13: Sum of squares and Mean square of Patients of different conditions on Quality of Life

Domain	**Sum of Squares**	***df***	**Mean Square**	***F***	**Sig.**
Physical	111.492	3, 140	37.164	1.772	.054
Psychological	18.669	3, 140	6.223	.633	.595
Social	11.894	3, 140	3.965	.855	.466
Environmental	28.108	3, 140	9.369	.473	.702
TOTAL	**68.049**	**3, 140**	**22.683**	**.175**	**.913**

Results in Table 14 indicated that there are differences between the Means (and Standard Deviations) of caregivers from the four different illness conditions. However, these differences were subjected to testing using the inferential statistics like the One-Way ANOVA to find out whether a significant difference exists. The results are shown in Table 15

Objective 4: Differences in caregivers illness perceptions of patients

Table 14 : Means and Standard deviations of Caregiver of different conditions on Illness Perception

Variables	**HIV/AIDS**		**SCHIZOPHRENIA**		**DIABETES**		**STROKE**	
	M	**SD**	**M**	**SD**	**M**	**SD**	**M**	**SD**
Views about	127.46	6.96	124.71	6.11	123.72	7.11	123.84	8.25

illness								
Possible Causes	42.69	9.28	53.20	6.19	44.11	9.06	46.63	10.97
Total Illness Perception	**170.15**	**12.49**	**177.91**	**9.72**	**167.83**	**10.46**	**170.47**	**16.37**

Results in Table 15 revealed that in total, there was a significant difference between the four different conditions on caregivers perception of illness [*F* (3, 140) = 4.735, *p* = .004]. At the subscale levels too there was a significant difference between the four diseases on Views about illness [*F* (3, 140) = 2.687, *p* = .049] as well as Possible Causes [*F* (3, 140) = 10.875, *p* = .000]. The Scheffe post hoc test was used to find out the exact differences between the groups. It was revealed that for views about illness, HIV/AIDS caregivers have more significant scores than Diabetes caregivers. For causes of illness, it was revealed that Schizophrenia caregivers have more significant scores than HIV/AIDS caregivers as well as Schizophrenia caregivers having more significant scores than Diabetes caregivers. In total, Schizophrenia caregivers have more significant scores than HIV/AIDS caregivers and Diabetes caregivers. Hence, the objective that different group of caregivers would have different illness perception was supported by the data.

Table 15: Sum of squares and Means squares of Caregivers of different conditions on Illness Perception

	Sum of Squares	***Df***	**Mean Square**	***F***	**Sig.**	**Scheffe Post Hoc Comparison**
Views about illness	393.676	3, 140	131.225	2.687	.049	HIV/AIDS>Diabetes
Possible	2541.768	3,	847.256	10.875	.000	SCHIZOPHRENIA>HIV/AIDS

Causes		140				SCHIZOPHRENIA >Diabetes
Total Illness Perception	**2042.705**	**3, 140**	**680.902**	**4.735**	**.004**	**SCHIZOPHRENIA>HIV/AIDS, SCHIZOPHRENIA >Diabetes**

Objective 5: Differences in caregivers' quality of life

Table 16 : Means and Standard deviations of Caregivers of different conditions on Quality of Life

Variables	**HIV/AIDS**		**SCHIZOPHRENIA**		**DIABETES**		**STROKE**	
	M	**SD**	**M**	**SD**	**M**	**SD**	**M**	**SD**
Service	26.87	2.27	26.97	2.70	26.03	2.65	25.53	2.70
Family Assistance	29.43	8.68	28.77	7.36	31.25	8.87	31.42	8.57
Life Activities	39.44	2.70	41.57	3.25	41.64	4.70	39.74	3.89
Total	**95.74**	**9.51**	**97.31**	**8.56**	**98.92**	**11.18**	**96.68**	**12.08**

Results in Table 16 indicated that there are differences between the Means (and Standard Deviations) of caregivers from the four different illness conditions. However, these differences were subjected to testing using the inferential statistics, One-Way ANOVA to find out whether a significant difference exists. The results are shown in Table 17.

Results in Table 17 revealed that in total, there was no significant difference in quality of life (QOL) among four conditions of caregivers [*F*(3, 140) = 0.728, *p* = .537]. At the subscale levels too there was no significant difference between the four illness conditions on Service QOL [*F*(3, 140) = 2.145, *p* = .097] and Family Assistance QOL [*F*(3, 140) = 0.778, *p* = .508]. However, there was a significant difference between caregivers on Life Activities QOL [*F*(3, 140) = 4.113, *p* = .008]. The Scheffe post hoc analysis revealed that Diabetes caregivers have more significant scores than ART caregivers. Nevertheless, the objective that different group of caregivers would have significantly different quality of life was not supported.

Table 17: Sum of squares and Mean square of Caregivers of different conditions on Quality of Life

	Sum of Squares	***df***	**Mean Square**	***F***	**Sig.**	**Scheffe Post Hoc Comparison**
Service	41.220	3, 140	13.740	2.145	.097	-
Family Assistance	165.216	3, 140	55.072	.778	.508	-
Life Activities	157.765	3, 140	52.588	4.113	.008	Diabetes > HIV/AIDS
TOTAL	**222.982**	**3, 140**	**74.327**	**.728**	**.537**	**-**

CHAPTER FIVE

DISCUSSION OF RESULTS

5.0 Introduction

This study aims primarily to describe the quality of life of people living with chronic diseases. It explored the perceptions of the victims and their relatives of the chronic diseases. This study tested five objectives in its quest of examining illness perception and quality of life of patients and their caregivers.

Medication alone is not sufficient to meet the needs of these patients. The demands of caregiving for mentally ill patients are problematic, as caregivers often have to grapple with the societal stigma associated with mental illness, emotional stress caused by caring for a sick relative or the symptoms associated with a family member's illness, and the combined emotional and physical stress caused by the actions and/or attitudes of patients. In some cases, there is also a cost factor incurred by treatment. These demands have been described as burdens by Gibbons and colleagues (Gibbons et al.1984)

5.1 Differences between patients and caregivers illness perception

Difference in illness perception between patients and caregivers could either have a positive or negative influence in managing and coping with the illness condition. For instance in a case where a caregiver has a poor perception about the patient’s illness condition, there is likely to be poor psychological capacity to manage and cope with the illness. Also, patients with poor perception of their illness condition are likely to face challenges psychologically and emotionally managing and coping with the illness. A condition could be well managed by medication but if the patient is not well poised with the right illness perception, managing and coping with the condition will be difficult. The inability of a patient to psychologically reconcile with his/her illness condition or the inability of a caregiver to do so could worsen the illness state. There is a saying that there is no health without mental well-being. This is also plausible considering the WHO definition of health which emphasizes on mental well-being.

The implication of the findings from this study is that, irrespective of the difference in illness perception both caregivers and patients should have a sound perception of the patient's illness condition. However, the difference shouldn't be ignored because it could lead to difference in ideology and efforts in managing and coping with the condition. This could probably result in conflicting efforts in managing the illness.

Though the study reveals a difference in illness perception, factors that might account for the difference was not investigated since that wasn't within the scope of the study. It is however worth investigating for any existing factors that could account for the difference.

The implication of difference in illness perception also applies to the differences ascertained among the four illness conditions. As the results indicate, there is a difference in illness perception of caregivers as well as patients among the four illness conditions. This implies that, different illness conditions present different perceptions. It therefore means that patients and caregivers illness perception could vary depending on the illness condition they are dealing with. Though factors surrounding the difference have not been explored in this study, it is worth noting that the difference in illness perception among the four conditions may require different psychological management and coping mechanisms. Results from the post hoc test indicate the specific differences among the four conditions.

Caregivers had significantly more scores (total) than the patients on total illness perception as well as the possible causes of illness at the subscale level but there are no differences for views about illness.

This is in line with several studies which demonstrated that caregivers feel burdened more than their relatives as shown in the literature; Most people living with HIV/AIDS find it challenging to attend to daily tasks of living, participate in moderate to vigorous physical activities, or have sufficient energy or vitality to engage in an active social life while managing HIV/AIDS. Fatigue or low energy has been associated with both physical and psychological morbidity (Breitbart et al, 1998) and poor QOL (Zinkernagel et al, 1999) in persons with HIV/AIDS. In addition, fatigue and a CD4 T-cell count less than 500 are associated with physical limitations and disability (Ferrando et al, 1998). Among HIV-positive patients, disease progression is related to decreasing energy and increasing difficulties with daily activities and pain (Sarna et al, 1999).

Boye *et al* (2001) prospectively examined the relationship between relatives' distress and patients' symptoms and behaviors, but no clear relationship emerged between PANSS total score and the relatives' distress. High levels of emotional distress and burden were observed by (Ukpong, 2006) in the caregivers of schizophrenia patients in Nigeria which were significantly associated with positive and negative symptoms of schizophrenia.

Treatment-related worries and concerns about physical limitations and pain were also more common among partners.

There are significant differences between patients' illness perception and caregivers' perception in symptoms like, weight loss, fatigue, headaches, upset stomach, sleep difficulties, dizziness and loss of strength. There are also differences in views about duration of illness, seriousness of condition, impact of illness on self and others, serious financial consequences, effect of treatment, understanding the illness, emotions about the illness and the variations in the symptoms.

5.2 Differences in Patients' illness perception

Many researchers have described living with chronic illness, including Michael (1996) who reports how patients with chronic illnesses have integrated these into their lives. Rush deals with themes such as *being confronted with losses*, which implies not functioning as well as before, and being confronted with changed affinity with others; as well as a *fluctuating feeling*, which term describes a mix of frustration, guilt, anger and fear; and *changed routines* which lead to dilemmas about identity conflicts related to meeting the demands. Finally, *control over an altered life situation*, which includes support, learning about the disease, fighting against or striving to cope with the demands and making the illness meaningful, helps people to integrate the disease (Michael, 1996). These views about the illnesses were evident in this study as they were dominantly mentioned both by the patients and their caregivers. Due to lengthy disease processes and absence of cure, patients may perceive chronic timeline to be an inherent part of their illnesses. Therefore patients may have adjusted their behaviors' to manage the duration and subsequent impact of their illnesses on physical quality of life. It is also possible that other multiple factors influence physical quality of life and that timeline might have been outweighed by physical symptoms.

5.3 Differences in Patients' quality of life.

In total, there was no significant difference among the patients' quality of life as well as at the subscale levels too. This implies that none of the patients with the four diseases seem to have significant differences in their views about the concept, quality of life.

The results clearly indicate no significant difference in overall mean scores on the quality of life among patients of the four illnesses. However, caution should be taken when interpreting this since the study hasn't further done any analysis to control for other factors such as age, sex, occupation, and so on. This is because QoL is a multidimensional concept (WHOQOL Group 1995, Harrison et al. 1996, Haas 1999, Moons et al. 2006). This study is therefore however with the recognition that other potential factors as mentioned above are worth considering when assessing an individual's QOL. Though there hasn't been a significant difference in overall mean scores, the various domains of the QOL assessment present different mean scores among patients. Generally, the social domain scored the lowest for all four categories of patients, with the lowest being HIV/AIDS with a mean score of 9.43 and the highest being Diabetes with a mean score of 10.17. The implication here is that, considering the QOL of all the four categories of patients, they perform least in terms of their satisfaction concerning their social life. The highest score for diabetes could be due to the fact that, diabetic patients are largely not stigmatized or not incapacitated depending on the level of illness. The lowest score for HIV/AIDS is in line with existing evidence from similar studies (Bello and Bello 2013; Rao et al., 2012; Folasire et al, 2012). This could be tied to issues of stigma (including self-stigma) and other possible factors. Stigma draws an individual from social life to an extent, which subsequently contributes to diminishing their QOL. This is in line with existing evidence that explain the link between social life, stigma and QOL (Rao et al., 2012 & Folasire et al , 2012). This implies that healthcare and other service providers for HIV/AIDS patients should provide services with recognition that, social support plays a key role in QOL improvement.

In terms of the physical domain, stroke patients recorded the least mean score, whiles the HIV/AIDS patients recorded the highest score. This outcome is not so surprising since stroke patients are obviously physically incapacitated which is mostly not in the case of HIV/AIDS patients. Physical limitations of an individual incapacitate them in carrying out their normal daily functions. The implication is that, the QOL of the individual is affected to some extent. It is therefore worth recognizing that, people with low physical scores on quality of life should be handled in a way so as to enable them realize to a satisfactory level, their physical capabilities. In some situations, such patients need close assistance in their daily lives.

For the environment domain, HIV/AIDS patients recorded the lowest score whilst Diabetes recorded the highest score. This is somewhat surprising because one would expect the stroke patients to have recorded the lowest score, since they may be more likely to find it physically challenging to interact with the physical environment. However one could link the low score for HIV/AIDS group to issues of the social environment. This is because having a problem with the social environment could possibly affect ones judgment on how they perceive their interaction with the physical or general environment. For instance the issue of stigma among HIV/AIDS patients could limit their interaction with the physical or general environment. In such cases, HIV/AIDS patients should be given much social support as well as counselling to enable them interact fully with their physical or general environment.

With the psychological domain, the diabetes group scored lowest whilst the Schizophrenia group scored the highest. The high score for schizophrenia (as compared to the others) may need to be interpreted with caution since some other studies show that, some individuals can rate themselves as healthy individuals (Moons et al. 2005). An explanation for the surprisingly high score for the psychological domain for schizophrenia may be that, many patients with schizophrenia have poor insight into the presence of their illness (Lincoln et al. 2007, Picchioni & Murray 2007). The lowest score for diabetes may not be surprising because a study suggests that, diabetes could strongly affect the physical and psychological domains as compared to the other domains (Eljedi et al, 2006). The implication of the psychological domain scores for all the illness groups is that, psychological therapy should not only be limited to mental patients. Effectively managing diabetes therefore has to be with the recognition that patients need psychological support especially in coping with the illness.

Overall, one can see that despite the little differences in scores, these differences are not statistically significant. The results also generally show low scores for all the QOL domains. It therefore brings to mind the fact that, any of these illnesses could affect an individual's QOL. Though other studies might find some significant difference in QoL among these illnesses, this study does not establish any significant difference. One should however bear in mind that, the level of illness in terms of duration could account for any difference in QoL among various illnesses. Various studies conducted indicate that as HIV infection progresses, it affects the QoL of the individual (Bourgoyne & Saunders 2001, Costa et al 2003).

Another explanation for research findings related to satisfaction with QoL is that patients have adapted their standards of QoL downwards (Becker et al. 2005, Katschnig, 2006). Various studies conducted across the globe which report that as the HIV infection progresses, it affects the QoL of the individual (Bourgoyne & Saunders 2001, Costa et al 2003). Various factors apart from physical and mental health like employment status, age, gender, income, education, HIV stage, severity of HIV infection, and similar others are found to impinge on the QoL of PLHIVs (Cleary et al ,1993; Cowdery & Pesa, 2002).

In line with the above research, the study came out with the following as important for the QoL of the patient; Friends, family, people relative/friend/neighbor's time spent**,** work ,school and other occupational activities, the mental stability of patient and having enough money. Holding down a job certainly has a positive influence on the perception that an individual has of his or her role in society and it contributes towards improving self-esteem, which is considered to be an important aspect of QOL (Bohlke et al., 2008).

5.4 Differences in Caregivers' perception about neighbour's illness

According to the research, caregivers of the HIV/AIDS patients had significantly more different views about their patients' illness than those of diabetes. This is not surprising as stigma is so much associated with HIV/AIDS and most of them believe there is no cure and they therefore wait to die. Depending on the stage of the disease, the symptoms can be so devastating especially when the care is not adequate. Diabetes patients see the illness as one of the several diseases just as their caregivers once they are capable of managing their lives especially the diet and medication. Caregivers mostly adjust to the new life of the relative or spouse and are of immerse help to the patient. Some of them even act as treatment supporters.

On the possible causes of the conditions, mental health caregivers perceive the causes of the illness more significantly than the rest of the illnesses. Patients with mental illness usually attribute the causes of their condition to different factors due to the lack of insight into their conditions like the hallucinations, delusions and illusions. The reverse is true of the other illnesses as they can easily recount the real causes of their predicament. These thoughts of theirs are difficult to be erased by their caregivers making some of them to fall prey to such ideations.

Compared to findings with healthy subjects (Moons et al.2005) patients named health much more often as the important QoL area as was seen that 70% of the carers saw mental health to be moderately important in their relatives' recovery. This is not surprising, since schizophrenia is one of the most serious and disabling mental disorders (Mueser & McGurk 2004, Picchioni & Murray 2007).

In a study by Freeman and Simmons (1963), they observed that severe mental symptoms were most upsetting for the family members because the emergence of symptoms predicted re-hospitalization. A significant degree of symptom tolerance was noted by Creer and Wing (Creer Wing 1975) albeit at a great deal of internal distress and family burden: Physical, emotional and financial. The commonest distressing behaviors noted were those related to social withdrawal and other negative symptoms.

5.5 Differences in Caregivers quality of life

In total, there was no significant difference among the four disease conditions of caregivers on quality of life (QOL) and at the subscale levels too except for Life Activities QOL which revealed that Diabetes caregivers have more significant scores than HIV/AIDS caregivers. However, there was a significant difference between caregivers on Life Activities QOL .Patients' QOL score was lower than caregivers', but the difference was not statistically significant. This is in line with a study by Unruh et al, 2004 who found no significant difference between patient and general population in QOL scores. Perhaps the most striking research finding is a tendency for the partner's quality of life to be worse than that of the patient.

Partners of stroke patients found that the physical dependency, cognitive and communication deficits and psychological symptoms of their spouses meant that the spouse 'was not the same person'. This led to partners' describing a decrease in their marital satisfaction although, by contrast, most patients claimed they had no marital difficulties (Bethoux, et al, 1996).

Sexual satisfaction was mentioned by some caregivers in the study to be decreased as they spend most of their time battling with the symptoms of the illness.

Caregivers' perceptions of caregiving in the study were comparable to other studies with caregivers of stroke survivors [Grant et al , 2000]. These findings also add to the literature in demonstrating that caregiving can be a positive experience for some (McKevitt et al, 2009, Schulz et al , 2007, Kinney et al, 1995) and that both rewards and burdens can co-exist [Grant et al, 1998].

Research directed toward an understanding of relationship factors that influence positive and negative role perceptions and caregiver outcomes are particularly important for designing interventions to promote the well-being of both members of the dyad.HRQoL is a multidimensional construct that consists of at least three broad domains − physical, psychological, and social functioning − that are affected by one’s disease and/or treatment (Sprangers .2002).

Interestingly, most of the patients 82(56.9%) in the study were females. This significant finding speaks to a larger sociocultural issue, an unwritten code in Jamaica that says ‘Women are nurturers and carers’ and that ‘If there is a disabled child in the family, he or she is the responsibility of female family members, and in the case of a child, a grandparent.’ This unwritten code requires further exploration, but the latter half of this code in particular underpins the stigma that is often directed at the disabled and their caregivers by community members.

CHAPTER SIX

6.1 : MAIN FINDIINGS

The implication of the findings from this study is that, irrespective of the difference in illness perception both caregivers and patients should have a sound perception of the patient's illness condition. However, the difference shouldn't be ignored because it could lead to difference in ideology and efforts in managing and coping with the condition. This could probably result in conflicting efforts in managing the illness.

It therefore means that patients and caregivers illness perception could vary depending on the illness condition they are dealing with.

Due to lengthy disease processes and absence of cure, patients may perceive chronic timeline to be an inherent part of their illnesses. Therefore patients may have adjusted their behaviors' to manage the duration and subsequent impact of their illnesses on physical quality of life.

The results clearly indicate no significant difference in overall mean scores on the quality of life among patients of the four illnesses. Overall, one can see that despite the little differences in scores, these differences are not statistically significant. The results also generally show low scores for all the QOL domains. It therefore brings to mind the fact that, any of these illnesses could affect an individual's QOL.

In total, Mental Health Unit (MHU) caregivers have more significant scores than Ante-Retroviral Therapy (ART) caregivers and Diabetes clinic caregivers [F(4.735),p=0.004].

In total, there was no significant difference between the four clinics of caregivers on quality of life (QOL) and at the subscale levels too except for Life Activities QOL which revealed that Diabetes clinic caregivers have more significant scores than ART caregivers. However, there was a significant difference between caregivers on Life Activities QOL [*F* (3, 140) = 4.113, *p* = .008]. Patients' QOL score was lower than caregivers', but the difference was not statistically significant.

CONCLUSION

The study demonstrated that the perception of illness and quality of life differs between patients and their family caregivers; this implies that people will have different views about illness depending on the type of condition they are suffering from. Care must be taken when handling them.

A condition could be well managed by medication but if the patient is not well poised with the right illness perception, managing and coping with the condition will be difficult.

The support given by caregivers positively affects the QoL of patients as they help the patients in their daily activities, as well as helping them solve the financial problems. Some are also supported psychological and emotionally to able to integrate well into society.

Caregivers desire to see their neighbors relate well in society, have good mental health, and healthy lifestyle coupled with the carers' having a bigger say in the decision making process of the patient's care. This can be achieved if all the stakeholders play their part to bring about a comprehensive care to the patient and relieving the caregivers too from the burden they go through.

The results clearly indicate no significant difference in overall mean scores on the quality of life among patients of the four illnesses. However, caution should be taken when interpreting this since the study hasn't further done any analysis to control for other factors such as age, sex, occupation, and so on.

SUMMARY OF FINDINGS, CONCLUSION AND RECOMMENDATIONS

6.0 Introduction

The main objective of this research is to assess the Quality Of Life (QOL) of patients and their caregivers: An assessment of the perceptions of sufferers of chronic diseases and had the following specific objectives;

- To examine whether patients’ illness perception will be significantly different from caregivers’ perception.
- To determine whether different group of patients would have different perception about their illness.
- To explore whether different group of patients would have significantly different quality of life.
- To examine whether different group of caregivers would have significantly different perception about their relatives/neighbours’ illness
- To determine whether different group of caregivers would have significantly different quality of life.

6.2 Recommendations

Based on the findings of the study, the following recommendations are made;

1. In order to improve the QOL of both patients and their caregivers on chronic illness, the government and Non-Governmental Organizations need to support these groups of people in terms of communication such as developing special support groups that consists of patients, caregivers as well as health staff. They can share their knowledge, experiences, ways to handle crisis, improve treatment compliance, and many more.

2. It is recommended that clinical psychologist should be involved in the management of chronic diseases. The management of chronic diseases should not be left in the hands of clinicians alone because the study found that emotional and psychological trauma are associated with these diseases.
3. Hospitals should also consider adopting the mobile or home-based treatment modules for people living with chronic diseases. This will help to reduce the anxiety and the economic cost of transportation to health facilities every week or at scheduled days.
4. There is the need for treatment and follow-up as well as improvement in family intervention programs delivered by health services. These factors should be considered in future research in this area. Program design should take into account socio-cultural characteristics of the population attending a health service. Efficacy of such interventions needs to be proved since they could be beneficial not only for the patients, but also for the caregivers.

6.3 Suggestions for Further Research

Further research should be conducted to assess the contributions of the spouses'/caregiver's perceptions of the illness that may be associated with outcome in chronically ill patients and their partners.

6.4 Limitations of the Study

a. Medically diagnosed chronic illness patients who did not attend their disease units were not included in the study due to difficulty in locating them.

b. The study is cross-sectional; therefore, direction and causation among variables cannot be established. Longitudinal data would allow for the assessment of potential mediators to explain the relationship among independent and dependent variables.

REFERENCES

Abdel-Khalek, A. Quality of Life, Subjective well-being, and religiosity in Muslim college students. *Qual. Life Res.;*2010:*19*, 1133-1143.

Addington-Hall JM, MacDonald LD, Chamberlain J, Freeling P, Bland JM, Raferty J. Randomised controlled trial of effects of coordinating care for terminally ill cancer patients. *BMJ* 1992;305:1317–22.

Agyei-Mensah S, de-Graft Aikins A (2010): Epidemiological transition and the double burden of disease in Accra, Ghana. Journal of Urban Health. 2010; 87(5):879–897.

Agyemang C, Attah-Adjepong G, Owusu-Dabo E, de-Graft Aikins A, Addo J, Edusei AK, Nkum B, Ogedegbe G (2012): Stroke in Ashanti region of Ghana: an urgent need for action. Ghana Med J. 2012;46(2) Suppl:12–17.

Anderson, J.P., Kaplan, R.M., Berry, C.C., Bush, J.W., Rumbaut, R.G., 1989. Interday reliability of function assessment for a health status measure: the Quality of Well Being Scale. Medical Care 27, 1076-1083.

Andreasen, N.C., & Olsen, S. (1982). Negative vs. positive schizophrenia. *Archives of General Psychiatry, 39,* 789-794.

Angermeyer, M.C., Holzinger, A., Kilian, R. & Matschinger, H. 2001. Quality of life – as defined by schizophrenic patients and psychiatrists. International Journal of Social Psychiatry 47, 34-42.

Atkinson, M., Zibin, S. & Chuang, H. 1997. Characterizing quality of life among patients with chronic mental illness: A critical examination of the self-report methodology. The American Journal of Psychiatry 154, 99-105.

Atkinson, J.M., Coia, D.A., Gilmour, H. & Harper, J.P. 1996. The impact of education groups for people with schizophrenia on social functioning and quality of life. British Journal of Psychiatry 168, 199-204.

Au E, Loprinzi CL, Dhodapkar M, et al. Regular use of a verbal pain scale improves the understanding of oncology inpatient pain intensity. J Clin Oncol1994;12:2751–5.

Baker, F. & Intagliata, J. 1982. Quality of life in the evaluation of community support system. Evaluation and Program Planning 5, 69-79.

Barr RD, Furlong W, Dawson S, et al. An assessment of global health status in survivors of acute lymphoblastic leukemia in childhood. Am J Pediatr Hematol Oncol*1993;15:284–90.*[Medline][Web of Science]

Barry, M.M. & Zissi, A. 1997. Quality of life as an outcome measure in evaluating mental health services: A review of the empirical evidence. Social Psychiatry and Psychiatric Epidemiology 32, 38-47.

Bailer J, Rist F, Brauer W, et al (1994). Patient Rejection Scale: Correlations with symptoms, social disability and number of rehospitalizations. Eur Arch Psychiatry Clin Neurosci. 1994; 244:45–8.

Bamford J, Sandercock P, Warlow C, Gray M.(1986): Why are patients with acute stroke admitted to hospital? BMJ 1986;292: 1369-72

Barrowclough, C., Lobban, F.(2001): An investigation of models of illness in carers of schizophrenia patients using the Illness Perception Questionnaire. British Journal of Clinical Psychology;2001: 40, 371–385.

Beach SR, Schulz R, Yee JL, Jackson S.(2000): Negative and positive health effects of caring for a disabled spouse: longitudinal findings from the caregiver health effects study. Psychology & Aging. 2000;15(2):259–271.

Becker, T., Leese, M., Krumm, S., Ruggeri, M., Vázquez-Barquero, J.L. & the EPSILON study group. 2005. Needs and quality of life among patients with schizophrenia in five European centres. What is the impact of global functioning scores? Social Psychiatry and Psychiatric Epidemiology 40, 628-634.

Bengtsson-Tops, A. & Hansson, L. 1999. Subjective quality of life in schizophrenic patients living in the community. Relationship to clinical and social characteristics. European Psychiatry 14, 256-263.

Bleyer WA.(2002): Cancer in older adolescents and young adults: epidemiology, diagnosis, treatment, survival, and importance of clinical trials. *Med Pediatr Oncol2002*; *38:1*–10.

Bonsu WK (2012): A comprehensive review of the policy and programmatic response to chronic non-communicable disease in Ghana. Ghana Med J. 2012; 46(2) Suppl: 69–78

Bowling, A. 2003. Current state of the art in quality of life measurement. In Carr, A.J., Higginson, I.J. & Robinson, P.G. (Eds.) Quality of Life. BMJ Publishing Group, London, UK. p. 1-8.

Bowling, A. 2005. Measuring health. A review of quality of life measurement scales. 3rd ed. Open University Press, Berkshire, UK.

Boyd, M. 2005. Psychiatric nursing. Contemporary practice. 3rd ed. Lippincott Williams & Wilkins, Philadelphia, USA.

Boye, B., Bentsen, H., Ulstein, I., Notland, T. H., Lersbryggen, A., Lingjaerde, O., et al. (2001). Relatives' distress and patients' symptoms and behaviours: A prospective study of patients with schizophrenia and their relatives. *Acta Psychiatrica Scandinavica, 104,* 42-50.

Browne G, Roberts J, Watt S, Gafni A, Stockwell M, Alcock S.(1994): Community rehabilitation: strategies, outcomes, expenditures. *Can J Rehabil* 1994; 8:9–22.

Cameron JI Franche R, Cheung AM, Stewart DE:(2006): Lifestyle interference and emotional distress in family caregivers of advanced cancer patients**.**

Canam C Acorn S: (1999): Quality of life for family caregivers of people with chronic health problems. *Rehabilitation Nursing* 1999, 24:192-196.

Carr AJ, Higginson IJ.(2001):Are quality of life measures patient centred? BMJ. 2001;14(7298):1357–1360. doi: 10.1136/bmj.322.7298.1357

Carr, A.J., Gibson, B. & Robinson, P.G. 2003. Is quality of life determined by expectations or experience? In Carr, A.J., Higginson, I.J. & Robinson, P.G. (Eds.) Quality of life. BMJ Books, London, UK.
p. 9-18.

Chambers, M. 1998. Interpersonal mental health nursing: research issues and challenges. Journal of Psychiatric and Mental Health Nursing 5, 203-211.

Charmaz K. (1983): Loss of self: a fundamental form of suffering in the chronically ill. Sociology of health & illness. 1983;5(2):168–195.

Chan, S. & Yu, I.W. 2004. Quality of life of clients with schizophrenia. Journal of Advanced Nursing 45, 72-83.

Chumbler NR, Rittman MR, Wu SS. (2008): Associations in sense of coherence and depression in caregivers of stroke survivors across 2 years. J Behav Health Serv Res. 2008;35(2):226–34. doi: 10.1007/s11414-007-9083-1.

Clark, E.H. 2004. Quality of life: a basis for clinical decision-making in community psychiatric care. Journal of Psychiatric and Mental Health Nursing 11, 725-730.

Cleeland CS, Gonin R, Hatfield AK, et al.(1994): Pain and its treatment in outpatients with metastatic cancer. N Engl J Med1994*;* 330:592–*6.*

Cleary, M., Walter, G. & Hunt, G. (2005) The experience and views of mental health nurses regarding nursing care delivery in an integrated, inpatient setting. International Journal of Mental Health Nursing 14, 7277.

Cohn, E. & Larson, E. 2007. Improving participant comprehension in the informed consent process. Journal of Nursing Scholarship 39, 273-280.

Cummins RA.(1997): Comprehensive Quality of Life Scale for adults. Australia: Deakin University, School of Psychology; 1997. (Manual ComQoL-A5).

Danovitch, I. & Endicott, J. 2008. Quality of life measures. In Rush, A.J., First, M.B., Blacker, D. (Eds.)
Handbook of Psychiatric Measures. American Psychiatric Publishing, Washington DC, USA. p. 125140.

Das Chagas Medeiros MM, Ferraz MB, Quaresma MR. The effect of rheumatoid arthritis on the quality of life of primary caregivers. J Rheumatol. 2000;27:76–83. [PubMed

De-Graft Aikins A, Anum A, Agyemang C, Addo J, Ogedegbe O.(2012): Lay representations of chronic diseases in Ghana: implications for primary prevention. Ghana Med J. 2012;46(2) Suppl:59–68.

De-Graft Aikins A, Boynton P, and Atanga LL (2010): Developing Effective Chronic Disease Prevention in Africa: insights from Ghana and Cameroon. Global Health. 2010; 6:6.

de-Graft Aikins A, Unwin N, Agyemang C, Allotey P, Campbell C, Arhinful DK (2012): Tackling Africa's Chronic Disease Burden: from the local to the global (Editorial) [21 February 2012];Global Health. 2010 6:5. Available at http://www.globalizationandhealth.com/series.

Fabrega H. Jr. Problems implicit in the cultural and social study of depression. *Psychosomatic Medicine.*1974; 36, 377-98.

Fahy, T., Kent, A., Tattan, T., Van Horn, E. & White, I. 1999. Predictors of quality of life in people with severe mental illness: Study methodology with baseline analysis in the UK700 trial. The British Journal of Psychiatry 175, 426-432.

Fayers, P.M. & Machin, D. 2007. Quality of life. Assessment, analysis and interpretation. 2nd ed. John Wiley & Sons, New York, USA.

Feeny DH, Furlong WJ, Torrance GW, et al.(2002): Multiattribute and single-attribute utility functions for the health utilities index mark 3 system. Med Care2002*;*40*:*113–*28.*

Feeny DH, Torrance GW, Furlong WJ. (1996): Health Utilities Index. In: SpilkerB, ed. Quality of life and pharmacoeconomics in clinical trials, *2nd edn. Philadelphia: Lippincott-Raven,* 1996*:*239–*52.*

Felder-Puig R, Frey E, Sonnleitner G, et al. German cross-cultural adaptation of the Health Utilities Index and its application to a sample of childhood cancer survivors. Eur J Pediatr*2000;159:283–8.*[CrossRef][Medline]

Ferrans CE. (1996): Development of a conceptual model of quality of life. Inquiry for nursing practice. 1996;14(4):248–254.

Figueiras, M. J., Weinman, J. (2003). Do similar patient and spouse perceptions of myocardial infarction predict recovery? Psychology & Health, 18, 201–216.

Fortune, D. G., Smith, J. V., Garvey, K (2005): .Perceptions of psychosis, coping, appraisals, and psychological distress in the relatives of patients with schizophrenia: An exploration using self-regulation theory. British Journal of Clinical Psychology;2005:44, 319–331.

Francioni FF, Silva DMG. (2002): The acceptance process in living with diabetes mellitus: considerations on the environments influence [In Portuguese]. *Texto Contexto Enfermagem*.2002; 11, 36-43.

Gråwe RW & Løvaas A-L. 1994. Quality of life among schizophrenic in- and out-patients. Nordic Journal of Psychiatry 48, 147-151.

Goldney RD, Pjillips PJ, Fisher LJ, Wilson DH. (2004): Diabetes, depression and quality of life. Diabetes Care 2004;27(5):1066–70.

Grootendorst PV, Feeny DH, Furlong W. Does it matter whom and how you ask? Inter- and intra-rater agreement in the Ontario Health Survey. J Clin Epidemiol1997;50:127–35.

Gupta, S., Kulhara, P. & Verma, S.K. 1998. Quality of life in schizophrenia and dysthymia. Acta Psychiatrica Scandinavica 97, 290-296.

Haas, B.K. 1999. Clarification and integration of similar quality of life concepts. Journal of Nursing Scholarship 31, 215-220.

Hansson, L., Middelboe, T., Merinder, L., Bjarnason, O., Bengtsson-Tops, A., Nilsson, L., Sandlund, M., Sourander, A., Sørgaard, K.W. & Vinding, H. 1999. Predictors of subjective quality of life in schizophrenic patients living in the community. A Nordic multicentre study. International Journal of Social Psychiatry 45, 247-258.

Hagger, M. S., Orbell, S.(2003): A meta-analytic review of the common-sense model of illness representations. Psychology & Health; 2003;18, 141–184.

Hall, V., Reimar, W. T., Ole, H. & Nicolai, L., (2011). Diabetes in Sub Saharan Africa

Han B, Haley WE.(1999): Family caregiving for patients with stroke. Review and analysis. Stroke. 1999;30(7):1478–1485.

Heijmans, M., De Ridder, D., Bensing, J.(1999): Dissimilarity in patients' and spouses' representations of chronic illness. Explorations of relations to patient adaptation. Psychology & Health;1999:14, 451–466.

Helder, D. I., Kaptein, A. A., van Kempen, G. M., van Houwelingen, J. C., Roos, R. A.(2001): Impact of Huntington's disease on quality of life. Movement Disorders;2001:16, 325–330.

Higginson I, Wade A, McCarthy M.(1990): Palliative care: views of patients and their families. *BMJ* 1990;301:277–81.

***Hodgkins M**, Albert D, Daltroy L. Comparing patients' and their physicians' assessments of pain. Pain1985;23:273–7*

Hofer, A., Kemmler, G., Eder, U., Edlinger, M., Hummer, M. & Fleischhacker, W.W. 2004. Quality of life in schizophrenia: The impact of psychopathology, attitude towards medication, and side effects. Journal of Clinical Psychiatry 65, 932-939.

Holmes, S. 2005. Assessing the quality of life – reality or impossible dream? A discussion paper. International Journal of Nursing Studies 42, 493-501.

Honkonen, T., Saarinen, S. & Salokangas, R.K.R. 1999. Deinstitutionalization and schizophrenia in Finland. II: Discharged patients and their psychosocial functioning. Schizophrenia Bulletin 25, 543-551.

Howk, C. 2002. Hildegard E. Peplau. Psychodynamic nursing. In Tomey, A.M. & Alligood, M.R. (Eds.) Nursing theorists and their work. 5th ed. Mosby, St. Louis, Missouri, USA. p. 379-398.

Janse AJ, Gemke RJ, Uiterwaal CSPM, et al.(2004) Quality of life: patients' and doctors' don't always agree. A meta-analysis. *J Clin Epidemiol2004; 57:653–61*.

Jones, D. A., & Peters, T. J. (1992). Caring for elderly dependants: effects on the carer's quality of life. *Age Ageing*, 21, 421-8.

Kaas, M.J., Lee, S. & Peitzman, C. 2003. Barriers to collaboration between mental health professionals and families in the care of persons with serious mental illness. Issues in Mental Health Nursing 24, 741-756.

Kaiser, W., Priebe, S., Barr, W., Hoffmann, K., Isemann, M., Röder-Wanner, U-U. & Huxley, P. 1997. Profiles of subjective quality of life in schizophrenic in- an out-patient samples. Psychiatry Research 66, 153-166.

Kaptein, A. A., Helder, D. I., Scharloo, M., van Kempen, G. M. J., Weinman, J., van Houwelingen, J. C., Roos, R. A. C.(2006): Illness perceptions and coping explain well-being in patients with Huntington's disease. Psychology & Health;2006: 21, 431–446.

Karow, A., Pajonk, F-G., Reimer, J., Hirdes, F., Osterwald, C., Naber, D. & Moriz, S. 2008. The dilemma of insight into illness in schizophrenia: self- and expert-rated insight and quality of life. European Archives of Psychiatry and Clinical Neuroscience 258, 152-159.

Kleinman A. *The illness narratives: suffering, healing and the human condition*. Basic Books, Inc. New York. 1988

Koivumaa-Honkanen, H.T., Honkanen, R., Antikainen, R., Hintikka, J. & Viinimäki, H. 1999. Self-reported life satisfaction and treatment factors in patients with schizophrenia, major depression and anxiety disorder. Acta Psychiatrica Scandinavica 99, 377-384.

Kratzer J.(2012): Structural Barriers to coping with Type 1 Diabetes Mellitus in Ghana: experiences of diabetic youth and their families. Ghana Med J. 2012; 46(2) Suppl:39–45.

Lawrence C. *Medicine in the making of modern Britain.*1994; *1700-1920.* Routledge, London.

Leventhal H, Diefenbach M, Leventhal EA.(1992): Illness cognitions: using common sense to understand treatment adherence and affect cognition interactions. Cogn Ther Res 1992; 16:143–63.

Leventhal, H., Nerenz, D. R., Steele, D. J.(1984): Illness representations and coping with health threats. In: A. Baum, S. E. Taylor & J. E. Singer (Eds.), *Handbook of Psychology and Health*;1984. (Vol. IV, pp. 219–252). Hillsdale, NJ: Erlbaum.

Lewis MA, McBride CM, Pollak KI, Puleo E, Butterfield RM, Emmons KM. Understanding health behavior change among couples: an interdependence and communal coping approach. Soc Sci Med. 2006;62:1369–80. [PubMed]

Lincoln, T.M., Lüllmann, E. & Rief, W. 2007. Correlates and long-term consequences of poor insight in patients with schizophrenia. A systematic review. Schizophrenia Bulletin 33, 1324-1342.

Low JT, Payne S, Roderick P. (1999): The impact of stroke on informal carers: a literature review. Soc Sci Med. 1999;49(6):711–725. doi: 10.1016/S0277-9536(99)00194-X.

Lupton D. *Medicine as culture: illness, disease and the body in Western societies*, 1994 ;(p. 93) Sage Publishing, London.

Mant J, Carter J, Wade DT, et al.(2000): Family support for stroke: a randomised controlled trial. *Lancet2000*; *356:808*–13.

Marwaha, S., Johnson, S., Bebbington, P., Angermeyer, M.C., Brugha, T., Azorin, J-M., Kilian, R., Konfeld, A. & Toumi, M. 2008. Correlates of subjective quality of life in people with schizophrenia. The Journal of Nervous and Mental Disease 196, 8794.

McKevitt C, Redfern J, Mold F, Wolfe C.(2004): Qualitative studies of stroke: A systematic review. Stroke. 2004;35:1499–1505. doi: 10.1161/01.STR.0000127532.64840.36

Meeberg, G.A. 1993. Quality of life: a concept analysis. Journal of Advanced Nursing 18, 32-38.

Megens, Y. & van Meijel, B. 2006. Quality of life for long-stay patients of psychiatric hospitals: a literature study. Journal of Psychiatric and Mental Health Nursing 13, 704-712.

Michael SR.(1996): Integrating chronic illness into one’s life- a phenomenological inquiry.1996; 3, 251-267. *Journal of Holistic Nursing*

Moons, P., Budts, W. & De Geest, S. 2006. Critique on the conceptualisation of quality of life: A review and evaluation of different conceptual approaches. International Journal of Nursing Studies 43, 891-901.

Mubarak, A.R. 2005. Social functioning and quality of life of people with schizophrenia in the Northern region of Malaysia. Australian e-Journal for the Advancement of Mental Health [serial on the Internet], 4 (3). http://www.auseinet.com/journal/vol4iss3/mubarak.pdf . (Accessed 30.3.2008.)

Murphy, H. & Murphy, E.K. 2006. Comparing quality of life using the World Health Organization Quality of Life measure (WHOQOL-100) in a clinical and nonclinical sample: Exploring the role of self-esteem, selfefficacy and social functioning. Journal of Mental Health 15, 289-300.

Najafi, M., Sheikhvatan, M., Montazeri, A. & Sheikhfathollahi, M(2009): Reliability of World Health Organization's Quality of Life-BREF versus Short Form 36 Health Survey questionnaires for assessment of quality of life in patients with coronary artery disease. *Journal of Cardiovasc Med (Hagerstown)*,2009,10(4), 316-321.

Nyhlin KT, Lithner F, Norberg A.(1987): Experience of being diabetic –"It is up to oneself to manage". 1987;1, 59-62. *Scandinavian Journal of Caring Sciences*

Nørholm, V. & Bech, P. 2006. Quality of life in schizophrenia patients: Association with depressive symptoms. Nordic Journal of Psychiatry 60, 32-37.

Northouse LL, Mood D, Kershaw T, Schafenacker A, Mellon S, Walker J, Galvin E. et al. Quality of life of women with recurrent breast cancer and their family members. J Clin Oncol. 2002;20:4050–64. doi: 10.1200/JCO.2002.02.054. [PubMed] [Cross Ref]

O'Boyle, C.A., McGee, H.M., Hickey, A., Joyce, C.R.B., Browne, J., O'Malley, K. & Hiltbrunner, B. 1993. The Schedule for the Evaluation of Individual Quality of Life (SEIQoL). Administration manual. Department of Psychology, Royal College of Surgeons in Ireland, Dublin, Ireland.

Padilla, G.V., Grant, M.M. & Ferrell, B. 1992. Nursing research into quality of life. Quality of Life research 1, 341-348.

Parsons T.(1951): *The social system*.1951; Glencoe Free Press, Glencoe, Illinois.

Patel, K.K., Veenstra, D.L. & Patrick, D.L. 2003. A review of selected patient-generated outcome measures and their application in clinical trials. Value in Health 6, 595-603.

Peplau, H.E. 1991. Interpersonal Relations in Nursing. A Conceptual frame of reference for psychodynamic nursing. Springer Publishing, New York, USA.

Peplau, H.E. 1994. Quality of life: an interpersonal perspective. Nursing Science Quarterly 7, 10-15.

Picchioni, M.M. & Murray, R.M. 2007. Schizophrenia. British Medical Journal 335, 91-95.

Pierret J. (2003): The illness experience: state of knowledge and perspectives for research. Sociology of health & illness. 2003;25:4–22.

Priebe, S. & Fakhoury, W.K.H. 2008. Quality of life. In Clinical handbook of schizophrenia Mueser, K.T. & Jeste, D.V. (Eds.) Clinical handbook of schizophrenia. The Guilford Press, New York, USA. p. 581-591.

Potasznik H, Nelson G (1984): Stress and social support: The burden experienced by the family of a mentally ill person. Am J Community Psychol. 1984;12:589–607.

Rowbothan M, Harden N, Stacey B, et al. Gabapentin for the treatment of postherpetic neuralgia: a randomized controlled trial. JAMA1998;280:1837–42

Zahid MA, Ohaeri JU:(2010): Relationship of family caregiver burden with quality of care and psychopathology in a sample of Arab subjects with schizophrenia. BMC Psychiatry 2010,10:71.

Rhee YS, Yun YH, Park S, Shin DO, Lee KM, Yoo HJ, Kim JH. et al. (2008): Depression in family caregivers of the elderly: the feeling of burden as a predictor of depression. J Clin Oncol. 2008;26:5890–5. doi: 10.1200/JCO.2007.15.3957.

Rocca, P., Giugiario, M., Montemagni, C., Rigazzi, C., Rocca, G. & Filippa, B. 2009. Quality of life and psychopathology during the course of schizophrenia. Comprehensive Psychiatry 50, 542-548

Rubin RR, Peyrot M.(1999): Quality of life and diabetes. *Diabetes Metabolism Research and Reviews* .1999; 15, 205-218. .

Saigal S, Feeny D, Rosenbaum P, et al. Self-perceived health status and health-related quality of life of extremely low-birth-weight infants at adolescence. JAMA*1996;276:453–9.*

Salokangas, R.K., Honkonen, T., Stengård, E. & Koivisto, A-M. 2006. Subjective life satisfaction and living situation of persons in Finland with long-term schizophrenia. Psychiatric Services 57,373-381.

Saunders, J. C. & Byrne, M. M. (2002). A thematic analysis of families living with schizophrenia. *Archives of Psychiatric Nursing, 16*, 217-223.

Schulz R, Beach SR. (1999): Caregiving as a risk factor for mortality: the Caregiver health effects study. J Am Med Assoc. 1999;282(23):2215–2219. doi: 10.1001/jama.282.23.2215.

Schulz R, Hebert RS, Dew MA, Brow SL, Scheier MF, Beach SR, Czaja SJ, Martire LM, Coon D, Langa KM, Gitlin LN, Stevens AB, Nichols L.(2007): Patient suffering and caregiver compassion: New opportunities for research, practice, and policy.The Gerontologist. 2007; 47:1–13.

Schulz R, Martire LM. (2004): Family caregiving of persons with dementia: prevalence, health effects and support strategies, 2004 May-Jun;12(3):240-9. http://www.ncbi.nlm.nih.gov/pubmed/15126224

Schwartz CE, Sprangers MAG.(2000): Adaptation to Changing Health. Response Shift in Quality of Life Research. Washington DC: American Psychological Association, 2000

Smith J, Birchwood M, Cochrane R, et al. (1993):The needs of high and low expressed emotion families: A normative approach. Soc Psychiatry Psychiatr Epidemiol. 1993;28:11–16.

Sneeuw KC, Aaronson NK, Sprangers MA, et al. Value of caregiver ratings in evaluating the quality of life of patients with cancer. J Clin Oncol1997;15:1206–17.

Spilker BG, ed. Quality of Life and Pharmacoeconomics in Clinical Trials. Philadelphia: Lippincott-Raven, 1996

Stein RE, Jessop DJ. Functional status II(R). A measure of child health status. Med Care1990;28:1041–55.

Tagoe H (2012): Household burden of chronic disease in Ghana. Ghana Med J. 2012; 46(2) Suppl:54–58.

***Tetteroo E**, Graaf van der Y, Bosch JL, et al. Randomised comparison of primary stent placement versus primary angioplasty followed by selective stent placement in patients with iliac-artery occlusive disease.* Lancet*1998;351:1153–9.*[CrossRef][Medline][Web of Science]

Thornicroft, G. & Tansella, M. 2004. Components of a modern mental health service: A pragmatic balance of community and hospital care. British Journal of Psychiatry 185, 283-290.

Toombs K.(1993): *The meaning of illness. A phenomenological account of the different perspective of physicians and patients*. 1993; Kluwer Academic Publishers, London.

***Tetteroo E**, Graaf van der Y, Bosch JL, et al. Randomised comparison of primary stent placement versus primary angioplasty followed by selective stent placement in patients with iliac-artery occlusive disease.* Lancet*1998;351:1153–9.*[CrossRef][Medline][Web of Science]

United Nations, (2011): Draft Political Declaration of the High-level Meeting on the prevention and control of non-communicable diseases. 2011. Sep, [21 February 2012]. http://www.un.org/en/ga/ncdmeeting2011/pdf/NCD_draft_political_declaration.pdf

Vaughn, C. E., & Leff, J.P. (1976). The influence of family and social factors on the course of psychiatric illness. A comparison of schizophrenic and depressed neurotic patients. *The British Journal of Psychiatry The Journal of Mental Science, 129,* 125-137.

Veenhoven R. (2000): The four qualities of life ordering concepts and measures of the good life. J Happiness Stud. 2000;14:1–39. doi: 10.1023/A:1010072010360.

Wee H-L, Cheung Y-B, Li S-C, Fong K-Y, Thumboo J. (2005): The impact of diabetes mellitus and other chronic medical conditions on health-related quality of life: is the whole greater than the sum of its parts? Health and quality of life outcomes 2005:3–12.

White CL, Lauzon S, Yaffe MJ, Wood-Dauphinee S.(2004): Toward a model of quality of life for family caregivers of stroke survivors. Quality of Life Research. 2004;13(3):625–638. [PubMed]

WHOQoL ,measuring quality of life. http://www.who.int/mental_health/media/68.pdf.(accessed on 20th May, 2015)

Wilkinson AM, Joanne Lynn.(2005) Caregiving for advanced chronic illness patients. Tech region Anesth Pain Manag. 2005;9:122–132. doi: 10.1053/j.trap.2005.06.004.

Winefield HR, Harvey EJ (1993): Determinants of psychological distress in relatives of people with chronic schizophrenia. Schizophr Bull. 1993; 19:619–25.

Zahid MA, Ohaeri JU:(2010): Relationship of family caregiver burden with quality of care and psychopathology in a sample of Arab subjects with schizophrenia. *BMC Psychiatry* 2010,10:71.

Appendix 1: Study Questionnaire

Questionnaire –PATIENTS

I am a student from UDS offering MPHIL programme in community Health and Development.

I am conducting a health facility based study to assess the Quality of Life (QOL) and illness perceptions of patients and their informal caregivers with chronic diseases so as to inform policy and development partners. Due to your experience and position you have been chosen to participate in the study.

All the information you provide will be handled in a strictly confidential manner. You do not have to reveal information that makes you uncomfortable if you do not want to, but if you are willing to share your experiences; it will be very helpful to me in understanding issues relating to chronic illnesses within the facilities.

Background Characteristics

This questionnaire asks for your views about your health status and quality of life. Please begin by

Providing the following information about yourself. Please check ( ) the best answer.

1. **Age:**______________________________
2. **Sex:**______________________________
3. **Religion:** Christianity [ ] Muslim [ ] Traditionalist [ ] Others________________________________
4. **What is your current status:** Single [ ] Married [ ] Separated [ ] Divorced [ ] Widowed [ ]
5. **How many children have you given birth to?**

None [ ] 1-2 [ ] 3-5 [ ] More than 5 [ ]

6. **Highest Educational Level Attained**: No formal ( ) 'O' levels or GCSEs ( ) 'A' level or Higher School Certificate Diploma ( ) Undergraduate ( ) Postgraduate ( )
7. Are you currently **ill**? Yes No
8. If something is wrong with your health what do you think it is?_______________illness/ problem

9. What is your religious affiliation? Please check ( ) the most appropriate answer.

______ Catholic ______ Muslim

______ Jewish ______ Other specify: ____________________

______ Protestant ______ None

....

....

10. Who do you currently live with? Please check ( ) the most appropriate answer.

______ Living alone Other, please explain:______________________

______ Living with spouse and/or children

______ Living with non-relative

....

....

11. What is your current living arrangement? Please check ( ) the most appropriate answer.

______ Living in own home ______ Living in an institution

______ Living in an apartment ______ Living in an assisted living facility

______ Living in a board and care facility ______ Other, please explain: ______________

____

12. What is your primary source of income? Please check ( ) all that apply.

_______ Savings, Interest Dividends _______ Annuity

_______ Pensions _______ Veterans' Benefits

_______ Family and Friends _______ Disability Insurance

_______ Stocks and Bonds _______ Job

_______ Social Security Other, please specify: ______________________

APPENDIX 2: WHOQOL-BREF

The following questions ask how you feel about your quality of life, health, or other areas of your life. I will read out each question to you, along with the response options. **Please choose the answer that appears most appropriate.** If you are unsure about which response to give to a question, the first response you think of is often the best one.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life **in the last four weeks.**

		Very poor	Poor	Neither poor nor good	Good	Very good

1.	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2.	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the last four weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3.	To what extent do you feel that Physical pain prevents you from doing what you need to do?	5	4	3	2	1
4.	How much do you need any					

	Medical treatment to function in your daily life?	5	4	3	2	1
5.	How much do you enjoy life?	1	2	3	4	5
6.	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
7.	How well are you able to concentrate?	1	2	3	4	5
8.	How safe do you feel in your daily life?	1	2	3	4	5
9.	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about how completely you experience or were able to do certain things in the last four weeks.

		Not at all	A little	Moderately	Mostly	Completely
10.	Do you have enough energy for everyday life?	1	2	3	4	5
11.	Are you able to accept your	1	2	3	4	5

	bodily appearance?					
12.	Have you enough money to meet your needs?	1	2	3	4	5
13.	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14.	To what extent do you have the Opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither poor nor good	Good	Very good
15.	How well are you able to get around?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor	Satisfied	Very satisfied

				dissatisfied		
16.	How satisfied are you with your sleep?	1	2	3	4	5
17.	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18.	How satisfied are you with your capacity for work?	1	2	3	4	5
19.	How satisfied are you with yourself?	1	2	3	4	5

20.	How satisfied are you with your personal relationships?	1	2	3	4	5
21.	How satisfied are you with your sex life?	1	2	3	4	5
22.	How satisfied are you with the support you get from your friends?	1	2	3	4	5

23.	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24.	How satisfied are you with your access to health services?	1	2	3	4	5
25.	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to how often you have felt or experienced certain things in the last four weeks.

		Never	Seldom	Quite often	Very often	Always
26.	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	5	4	3	2	1

Do you have any comments about the assessment?

[The following table should be completed after the interview is finished]

		Equations for computing domain scores	Raw score	Transformed scores*	
				4-20	0-100
27.	**Domain 1**	(6-Q3) + (6-Q4) + Q10 + Q15 + Q16 + Q17 + Q18 † + † + † + † + † + † + †	a. =	b:	c:
28.	**Domain 2**	Q5 + Q6 + Q7 + Q11 + Q19 + (6-Q26) † + † + † + † + † + †	a. =	b:	c:
29.	**Domain 3**	Q20 + Q21 + Q22 † + † + †	a. =	b:	c:
30.	**Domain 4**	Q8 + Q9 + Q12 + Q13 + Q14 + Q23 + Q24 + Q25 † + † + † + † + † + † + † + †	a. =	b:	c:

APPENDIX 3: ILLNESS PERCEPTION QUESTIONNAIRE (IPQ-R)

PATIENTS AND CAREGIVERS

Name……………………………… *Date*…………………………………

YOUR VIEWS ABOUT YOUR ILLNESS

Listed below are a number of symptoms that you may or may not have experienced since your illness. Please indicate by circling *Yes* or *No*, whether you have experienced any of these symptoms since your illness, and whether you believe that these symptoms are related to your illness

I have experienced this **This symptom is *related***
to

symptom *since my illness* ***my illness***

Pain	**Yes**	**No**	______________	**Yes**	**No**
Sore Throat	**Yes**	**No**	______________	**Yes**	**No**
Nausea	**Yes**	**No**	______________	**Yes**	**No**
Breathlessness	**Yes**	**No**	______________	**Yes**	**No**
Weight Loss	**Yes**	**No**	______________	**Yes**	**No**
Fatigue	**Yes**	**No**	______________	**Yes**	**No**
Stiff Joints	**Yes**	**No**	______________	**Yes**	**No**
Sore Eyes	**Yes**	**No**	______________	**Yes**	**No**
Wheeziness	**Yes**	**No**	______________	**Yes**	**No**
Headaches	**Yes**	**No**	______________	**Yes**	**No**
Upset Stomach	**Yes**	**No**	______________	**Yes**	**No**
Sleep Difficulties	**Yes**	**No**	______________	**Yes**	**No**
Dizziness	**Yes**	**No**	______________	**Yes**	**No**
Loss of Strength	**Yes**	**No**	______________	**Yes**	**No**

We are interested in your own personal views of how you now see your current illness.

Please indicate how much you agree or disagree with the following statements about your illness by ticking the appropriate box.

	VIEWS ABOUT YOUR ILLNESS	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
IP1	My illness will last a short time					
IP2	My illness is likely to be permanent rather than temporary					
IP3	My illness will last for a long time					
IP4	This illness will pass quickly					
IP5	I expect to have this illness for the rest of my Life					
IP6	My illness is a serious condition					
	VIEWS ABOUT YOUR ILLNESS	**STRONGLY DISAGREE**	**DISAGREE**	**NEITHER AGREE NOR DISAGREE**	**AGREE**	**STRONGLY AGREE**
IP7	My illness has major consequences on my life					
IP8	My illness does not have much effect on my life					
IP9	My illness strongly affects the way others see me					
IP10	My illness has serious financial consequences					
IP11	My illness causes difficulties for those who are close to me					
IP12	There is a lot which I can do to control my symptoms					
IP13	What I do can determine whether my illness					

	gets better or worse					
IP14	**The course of my illness depends on me**					
IP15	**Nothing I do will affect my illness**					
IP16	**I have the power to influence my illness**					
IP17	**My actions will have no effect on the outcome of my illness**					
IP18	**My illness will improve in time**					
IP19	**There is very little that can be done to improve my illness**					
IP20	**My treatment will be effective in curing my illness**					
IP21	**The negative effects of my illness can be prevented (avoided) by my treatment**					
IP22	**My treatment can control my illness**					
IP23	**There is nothing which can help my condition**					
IP24	**The symptoms of my condition are puzzling to me**					
IP25	**My illness is a mystery to me**					
IP26	**I don’t understand my illness**					
IP27	**My illness doesn’t make any sense to me**					
IP28	**I have a clear picture or understanding of my condition**					
IP29	**The symptoms of my illness change a great deal from day to day**					

IP30	**My symptoms come and go in cycles**					
IP31	**My illness is very unpredictable**					
IP32	**I go through cycles in which my illness gets better and worse.**					
IP33	**I get depressed when I think about my illness**					
IP34	**When I think about my illness I get upset**					
IP35	**My illness makes me feel angry**					
IP36	**My illness does not worry me**					
IP37	**Having this illness makes me feel anxious**					
IP38	**My illness makes me feel afraid**					

CAUSES OF MY ILLNESS

We are interested in what you consider may have been the cause of your illness. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused your illness rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for your illness. Please indicate how much you agree or disagree that they were causes for you by ticking the appropriate box.

	POSSIBLE CAUSES	**STRONGLY DISAGREE**	**DISAGREE**	**NEITHER AGREE NOR DISAGREE**	**AGREE**	**STRONGLY AGREE**
C1	**Stress or worry**					
C2	**Hereditary - it runs in my family**					
C3	**A Germ or virus**					
C4	**Diet or eating habits**					
C5	**Chance or bad luck**					

C6	**Poor medical care in my past**					
C7	**Pollution in the environment**					
C8	**My own behavior**					
C9	**My mental attitude e.g. thinking about life negatively**					
C10	**Family problems or worries caused my illness**					
C11	**Overwork**					
C12	**My emotional state e.g. feeling down, lonely, anxious, empty**					
C13	**Ageing**					
C14	**Alcohol**					
C15	**Smoking**					
C16	**Accident or injury**					
C17	**My personality**					
C18	**Altered immunity**					

In the table below, please list in rank-order the three most important factors that you now believe caused YOUR illness. You may use any of the items from the box above, or you may have additional ideas of your own.

The most important causes for me:-

1. ____
2. ____
3. ____

I am a student from UDS offering MPHIL programme in community Health and Development.

I am conducting a health facility based study to assess the Quality of Life (QOL) and illness perceptions of patients and their informal caregivers with chronic diseases so as to inform policy and development partners. Due to your experience and position you have been chosen to participate in the study.

All the information you provide will be handled in a strictly confidential manner. You do not have to reveal information that makes you uncomfortable if you do not want to, but if you are willing to share your experiences; it will be very helpful to me in understanding issues relating to chronic illnesses within the facilities.

APPENDIX 4: Background Information for Caregivers

BACKGROUND INFORMATION

1. Please list members residing in your household :

Name (First names only)	Relationship to client

2. Do you have a job at the present time? Yes No (if no, please skip to #5)

3. How many hours a week do you work or go to school? _____ hours per week

4. What is your occupation? ____

5 a. Who was your relative/friend/neighbor living with when he/she first became ill? (Check all that apply)

Alone
friend/roommate
with children
with parents
with significant other/spouse
other, please specify; _____________

5b. Where was your neighbor/relative friend living when he/she first became ill? (Check one)

in an apartment/home
in a boarding home
in an group home or halfway house
Homeless
at school/college
in an institution (i.e. hospital or nursing home)
in jail/prison
other, please specify:_____________

6 How old was your relative/friend/neighbor when he/she first became ill? _______years

7 a. Who is your relative/friend/neighbor living with now? (Check one)

Alone
friend/roommate
with children
with parents
with significant other/spouse
other, please specify; _______________

7 b. Where is you relative/friend/neighbor living now? (Check one)

in an apartment/home
in a boarding home
at school/college
in an institution (i.e. hospital or nursing home)

in an group home or halfway house

in jail/prison

Homeless

other, please specify:___________________

8. When was the last time the patient spent more than 7 consecutive overnights in your household?

Currently

Within the past year

Within the past month

Longer than a year ago

Within the past six months

9. In the time that you have been involved with the patient, how many times has he/she been Hospitalized? None ______ # times

10. What services has the patient received during the **past 6 months?** Don't know

Please check all that apply.

Community Support Program/

Assertive Case Management with Regular Community Outreach......................................

Job/Vocational Training...

Individual Psychiatrist Appointments...

Medication Group ....

Case Management...

Individual Therapy other than Case Management.............................

Groups including Living Skills, Social, Recreational, and Therapy groups....

Day Treatment...

General Medical Health……………………………………

Housing Support...

Any Other Services..?

Please Specify: ____

SERVICES

11. People are often required to talk with health professionals in trying to help their relative/friend/neighbor with mental illness. To what extent do the following statements reflect experiences you have had in getting treatment for your relative/friend/neighbor?

For each statement below, please tell us whether you **strongly agree, agree, have no opinion, disagree, strongly disagree** with it or **don't know.** Under each statement please check the corresponding box that best reflects your feelings.

a. The health care professionals that I have dealt with feel that I can play an important role in the treatment process.

Strongly Agree No Disagree Strongly Don’t Know/
Agree Opinion Disagree Doesn't Apply

b. The health care professionals that I have dealt with have given me as much information as I have needed.

Strongly Agree No Disagree Strongly Don’t Know/

Agree Opinion Disagree Doesn't Apply

c. I am comfortable questioning health care professionals about advice they give me.

Most of Some of No Rarely Never Don’t Know/ the time the time Opinion

Doesn't Apply

d. I would like to have more say than I do now about the services and medication my relative/friend/neighbor receives.

Strongly Agree Agree No Opinion Disagree strongly disagree don’t Know/

Doesn't Apply

e. Sometimes I feel that the health care professionals that I work with do not understand the problems people face in caring for a person with a mental illness.

Strongly Agree No Disagree Strongly Don’t Know/

Agree Opinion Disagree Doesn't Apply

f. I often wish that I knew more about mental illness when I talk with health care professionals.

Strongly Agree AgreeNo Opinion Disagree Strongly Disagree Don’t Know/

Doesn't Apply

g. I am comfortable in getting a second opinion when I have questions about advice I get from a health care professional.

Strongly Agree Agree No Opinion Disagree Strongly Disagree Don’t Know/Doesn't Apply

12. In general, how many contacts does your relative/friend/neighbor have with members of your household? Please fill in the blanks as appropriate.

Patient resides with you. Yes No

If yes, patient has spent _____ overnights away.

I and other members of my household and the client have seen each other ___times in the past month

I and other members of my household and the client have talked on the telephone __times in the past month.

I and other members of my household and the client have corresponded in the past month.

Yes No

No contact in the past two months Yes No

Other, please specify: ___________________________

13. In the **past six months** have you or any other member of your household had any meetings, any visits or phone calls **to** or **from** individuals who are treating the patient? (Doctors, Social workers, Psychologists, Counselors, Welfare workers).

If **yes**, please complete the following information:

	Number	Agencies involved
Personal Visits	______	________________
Phone Contacts	______	________________

Other: _______ _________________

Were any of these contacts of any help to you?

Yes No, please specify why not:___________________________

If no, i.e., you haven't had contact, would you like to have had contact with any of these people?

Yes No

FAMILY ASSISTANCE

14. Family and friends often take on responsibilities to provide care and support for a person with Chronic diseases. During the **past four weeks** how much support or supervision did you give to your relative/friend/neighbor in dealing with these particular problems/difficulties shown below and how did you feel about giving this support?

a. **Maintaining personal hygiene**	None	Little	Some	Much
How did you feel about giving such support?		Satisfied	Accepted	Dissatisfied
b. **Taking prescribed medication**	None	Little	Some	Much
How did you feel about giving such support?		Satisfied	Accepted	Dissatisfied
c. **Preparing meals**	None	Little	Some	Much
How did you feel about giving such support?		Satisfied	Accepted	Dissatisfied
d. **Getting up and getting dressed**	None	Little	Some	Much
How did you feel about giving such support?		Satisfied	Accepted	Dissatisfied

e. **Doing household chores** None Little Some Much

How did you feel about giving such support? Satisfied Accepted Dissatisfied

f. **Managing money** None Little Some Much

How did you feel about giving such support? Satisfied Accepted Dissatisfied

g. **Shopping for food, clothing, etc.** None Little Some Much

How did you feel about giving such support? Satisfied Accepted Dissatisfied

h. **Making use of leisure time** None Little Some Much

How did you feel about giving such support? Satisfied Accepted Dissatisfied

15. During the past four weeks, how much support or supervision did you give to help the patient control (overcome) the particular behaviors shown below?

a. **Socially embarrassing behavior** None Little Some Much

How did you feel about giving such support? Satisfied Accepted Dissatisfied

b. **Attention-seeking behavior** None Little Some Much

How did you feel about giving such support? Satisfied Accepted Dissatisfied

c. **Inappropriate sexual behavior** None Little Some Much

How did you feel about giving such support? Satisfied Accepted Dissatisfied

d. **Threatening or violent behavior** None Little Some Much

How did you feel about giving such support? Satisfied Accepted Dissatisfied

e. **Talk or threats of suicide** None Little Some Much

How did you feel about giving such support? Satisfied Accepted Dissatisfied

f. **Disturbing behavior at night** None Little Some Much

How did you feel about giving such support? Satisfied Accepted Dissatisfied

16. What is the hardest part in giving support to your relative/friend/neighbor? Please list the three hardest things to you, in order from most difficult to least difficult.

    1.

    2.

    3.

17. Are there things that you enjoy about supporting your relative/friend/neighbor? Please explain

    :____

    ____

LIFE ACTIVITIES AND GOALS

Now we are interested in knowing about your relative/friend/neighbor's abilities during the **past four weeks.**

18. ACTIVITY During the **past four weeks**, my relative/friend/neighbor has:

    Not been working or studying and/or going out at all

    Been working or studying; but requiring assistance or a reduction in hours worked

    Been working or studying in usual manner

19. DAILY LIVING During the **past four weeks,** my relative/friend/neighbor has:

    Not been managing personal care and/or not leaving home or institution at all

Been requiring assistance for daily activities and transport, but performing very light tasks

Been self-reliant in daily tasks; using public transport or driving

20. HEALTH During the **past four weeks,** my relative/friend/neighbor has:

Been feeling ill or poorly most of the time

Been lacking energy or not feeling well more than just occasionally been feeling well or great most of the time

21. SUPPORT During the **past four weeks,** my relative/friend/neighbor has:

Had infrequent support from family and friends or only when absolutely necessary

Been receiving only moderate support from family and friends

Been having good relationships with others and receiving support from family and friends

22. OUTLOOK During the **past four weeks,** my relative/friend/neighbor has:

Been seriously confused, frightened, or consistently anxious and depressed

Been having some periods of anxiety or depression because not fully in control of personal circumstances

Felt calm and positive in outlook and been accepting of personal circumstances

23. From your perspective, what do you think are the important treatment goals for your relative/friend/neighbor?

Goal 1: ____

How important is this goal to your relative/friend/neighbor?

Not at all											**Extremely**
important	1	2	3	4	5	6	7	8	9	10	**Important**

To what extent has your relative/friend/neighbor achieved this goal?

Not at all											**Completely**
achieved	1	2	3	4	5	6	7	8	9	10	**achieved**

Goal 2: ____

How important is this goal to your relative/friend/neighbor?

Not at all											**Extremely**
important	1	2	3	4	5	6	7	8	9	10	**Important**

To what extent has your relative/friend/neighbor achieved this goal?

Not at all											**Completely**
achieved	1	2	3	4	5	6	7	8	9	10	**achieved**

Goal 3:

____

How important is this goal to your relative/friend/neighbor?

Not at all											**Extremely**
important	1	2	3	4	5	6	7	8	9	10	**Important**

To what extent has your relative/friend/neighbor achieved this goal?

Not at all											**Completely**
achieved	1	2	3	4	5	6	7	8	9	10	**Achieved**

24. Please check a box below to indicate your rating of your relative/friend/neighbor's quality of life during the **past four weeks.**

Lowest quality means your relative/friend/neighbor's life is as bad as it could be. Highest quality means your relative/friend/neighbor's life is the best it could be.

LOWEST HIGHEST QUALITY

QUALITY 1 2 3 4 5 6 7 8 9 10

If your relative/friend/neighbor’s quality of life is less than he/she hoped for, how hopeful are **you** that he/she will eventually achieve his/her desired quality of life? (Check one)

Not at all Somewhat Moderately Very

How much control do **you** feel your relative/friend/neighbor has over the important areas of his/her life?

None Some A moderate amount A Great amount

25. How confident are you that your rating of your relative/friend/neighbor's quality of life is accurate? Please check the appropriate box.

Not at all Confident	Very Doubtful	Not very Confident	Quite Confident	Very Confident	Absolutely Confident

26. Which of the following factors do you think are most important in determining your relative/friend/ neighbor's quality of life?	Not important	Slightly important	Mildly important	Moderately important	Extremely important
Work, school or other occupational activities					
Your relative/friend/neighbor's feelings about him/herself					
Your relative/friend/neighbor's physical health					
Friends, family, people your relative/ friend/neighbor spends time with					
Having enough money					

Your relative/friend/neighbor’s ability to take care of him/herself					
Mental health					
Other, please specify:					

27. Have there been any important factors which would influence your relative/friend/neighbor's quality of life (i.e., deaths in the family, serious physical illness, accidents)? Please briefly explain.

____

28. Is there anything else you would like to tell us?

____

29. What is the most important thing that now needs to be done for your relative/friend/neighbor?

____

This is the end of the questionnaire. Thank you for giving your opinion and sharing your responses with us. If you have any questions about this questionnaire, please call or write Mr. Amoah Anetu Damien-0205643249 P.O.BOX 26 Regional Hospital, Bolgatanga

APPENDIX 5

GHANA HEALTH SERVICES
POST OFFICE BOX 26
BOLGATANGA
27TH APRIL, 2015

THE MEDICAL DIRECTOR
UPPER EAST REGIONAL HOSPITAL
P.0.BOX 26
BOLGATANGA

DEAR SIR,

PERMISSION TO USE FACILITY FOR DATA COLLECTION

As part of my MPHIL in Community Health and Development programme, I wish to use your august facility to gather data for my thesis on the topic, “Quality of Life and Illness perception of Clients’ and informal caregivers living with chronic diseases”.

The study areas would basically be Diabetic clinic, Mental Health Unit, ART clinic and Physiotherapy department and the method is by convenient sampling using questionnaire. The information obtained is strictly for academic purpose. If accepted, I would like to start on 29/04/15.Please be honored to inform the various unit in-charges on my behalf.

Counting on your usual response.

Thank You.

Sincerely Yours.
Amoah Anetu Damien
(Nursing Officer)

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