PSYCHO-SOCIAL SUPPORTS AND FAMILY INTEGRATION AS DETERMINANTS OF PALLIATIVE CARE OF TERMINALLY-ILL PATIENTS IN UNIVERSITY COLLEGE HOSPITAL, IBADAN NIGERIA

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CERTIFICATION

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DEDICATION

This research is dedicated to the most Sacred Heart of Jesus who has been the source of my strength from ages past.

To my late parents, my siblings, my children and grandchildren for their understanding and encouragement, and the souls of the departed faithfuls.

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ABSTRACT

Orthodox medical practice has brought about access to diagnosis and modern healthcare through the palliative care system to treat the terminally-ill, thereby improving their quality of life. This treatment of the terminally-ill utilises medical diagnostic interventions with little or no consideration for psychosocial supports and family integration which are at the core of the palliative care system. This study, therefore, investigated the psychosocial supports (diversional, behavioural, emotional, counselling services, companionship, spirituality, rehabilitative supports and regular visitation) and family integration (financial assistance, life-style modification and re-allocation of roles) as determinants of palliative care of terminally-ill patients at University College Hospital, (UCH), Ibadan, Nigeria.

The study adopted the survey research design. The UCH was purposively selected. Proportionate and stratified random sampling techniques were used to select 587 respondents, namely, 183 health workers (50 doctors, 83 nurses, 24 physiotherapists and 26 social workers), 202 terminally-ill patients and 202 family caregivers from purposively selected eight wards and three out-patient clinics. Three instruments were used: Psychosocial Support Scale (r=0.67), Family Integration Scale (r=0.65) and Palliative Care Services Scale (r=0.71). These were complemented with ten sessions of in depth interview with the health workers, terminally-ill patients and family caregivers. Two research questions were answered and three hypotheses tested at 0.05 level of significance. Data were analysed using descriptive statistics, Pearson product moment correlation, multiple regression and content analyses.

The respondents were 218 male, and 369 female with age of 38.54, ±SD=9.78; with 202 terminally-ill patients; cancer (86), cardiac problems (42), neurological disorders (33), end stage kidney problems (22) and HIV/AIDS (19). Psychosocial supports and family integration significantly correlated with palliative care of the terminally-ill ($F_{(12.189)}$= 25.25, R=.79); and jointly accounted for 62.0% of the variance in their palliative care. Psychosocial supports (β = .55) and family integration (β= .51) relatively contributed to the palliative care system. Components of psychological supports had significant positive relationship with palliative care as follows: emotional support (r=.69), diversional support (r=.54), behavioural support (r=.50) and counseling services (r=.45). Also, components of social supports had positive relationship with palliative care: regular visitation (r=.41), spirituality (r= .33), rehabilitative support (r= .308) and companionship (r= .066). Observed relationship among family integration factors and palliative care were: financial assistance (r=.65), life-style modification (r=.32) and reallocation of roles (r=.32). Problems facing the utilisation of palliative care system include: irregular training on palliative care for health workers (64.0%), problem of early diagnosis (62.0%), non-availability of pain control medication (58.2%) and non-affordability of treatment (23.0%). Patients expressed anxiety over the outcome of illness, difficulty in adaptation to life style modification and fear of death in the face of poor patient-health workers communication.

Psychosocial support and family integration positively influenced palliative care system for the terminally-ill patients at the University College Hospital, Ibadan, Nigeria. Therefore, adequate provision of funds, pain control medication and staff retraining are required to ensure effective treatment in palliative care. In addition, the terminally-ills and their family members should be appropriately counselled on the need for life-style modifications and role reallocation.

Keywords: Terminally ill patients, Palliative care, Psychosocial supports, Family integration.
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CHAPTER ONE

INTRODUCTION

1.1 Background to the study

Terminal illness is a medical term popularised in the 20th century to describe a disease that cannot be cured or adequately treated (Glare, Virik, & Jones, 2003). This term is more commonly used for progressive diseases like cancer, complicating heart disease, end stage kidney disease, neurological problems and HIV/AIDS (Pass, 2000; Morrison, 2006).

In traditional African societies, including Nigeria, health and disease are not only closely related, but also have religious and cultural contexts (Udoh, 2002). Among indigenous spiritual deities in the African societies, there is a prevailing belief about humanity's relationship to the supernatural forces, which have implication for health condition of the individuals (Udoh, 2000 & 2002). For instance, it is believed that the state of terminal illness in an individual is caused by the anger of the gods, the actions of wicked persons, or the anger of the displeased ancestors. Within this context, terminal illness can be caused by natural, supernatural and mystical factors (Boston 1984; Udoh, 2000). Natural causes are diseases brought about by natural factors and invisible media (Erinosho, 1989) while the supernatural causes are diseases originating from the actions of evil persons, witches and sorcerers. Mystical causes are brought about by dissatisfaction of ancestors and deities (Udoh, 2000) and they are directed against individuals, families and communities (Oke, 1980; Erinosho, 1989).

Udoh (2002) explained that illnesses such as cough, scabies, small pox and epilepsy are considered to be of natural origin among the Igbo people of Eastern Nigeria. The Igbo people also believe that these diseases may be caused by invisible elements. The Yorubas of Western Nigeria believe that diseases such as cancer, small pox, measles, hepatitis, tuberculosis and mental illness attributed mostly to unnatural causes, evil persons, aggrieved deities or ancestors (Erinosho, 1987). As a result of these traditional beliefs, terminal illnesses are generally believed to be due to supernatural and mystical causes (Lucas & Hendrickse, 1990). Hence, there is the need for a traditional healthcare delivery system that is utilised in the care of patients with terminal illness.

The traditional medicine system which is the same as folk medicine is popular in the rural communities of Nigeria (Oke, 1989; Udoh, 2002). Given the consultative pressure from orthodox medical practitioners, its utilisation has not earned widespread government acceptance and recognition (Anderson, 1998). The main objection to traditional or folk medicine is based on

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personal and professional interests of orthodox medical practitioners, who have argued that indigenous medical practices are crude and unscientific (Sorochan, 1998).

Deducing from the above argument of the orthodox medical practitioners, it is, therefore, an accepted knowledge that the modern healthcare delivery system provides the best medical intervention, competence, state of the art physical assets and infrastructure to attend to terminal illnesses. However, there are some terminal illnesses that are fatal in their complexity, orientation and conclusion. They will surely lead to death, no matter the level of orthodox healthcare attention provided. The conclusive outcome cannot be reversed (Balogun, 2007). Such illness is reasonably expected to result in the death of the patient within a relatively short period of time.

In popular use, indicates a disease which will eventually end the life of the sufferer. A patient who has such an illness may be referred to as a terminal patient or terminally ill or simply terminal. Often, a patient is considered to be terminally ill when life expectancy is estimated to be six months or less, under the assumption that the disease will run its normal course (Borneman, 2004). A patient may be considered terminal, this is not a guarantee that the patient will die within six months (Taylor, 1988). Similarly, a patient with a slowly progressing disease, such as AIDS, may not be considered terminally ill because the best estimates of longevity were greater than six months. However, this does not guarantee that the patient will not die unexpectedly early (Grealish, Lomasney & Whiteman, 2000).

The medical personnel and their supportive staff do not give up and ignore or suspend the care given to the terminally ill (Collin, 2008). The patient is therefore transitioned into palliative care. Palliative care is a specialised care, focused not on cure but on the pain, symptoms, stress and quality of life associated with serious illness (Seymour, Clark & Winslow, 2004). World Health Organisation (2002) defined palliative care as an approach which improves the quality of life of patients and their families facing the problem associated with life threatening illness, through the prevention, and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems.

Soyannwo (2004) submits that palliative care is “the active holistic care of patients with advanced progressive illness, management of pain and other symptoms with provision of psychological, social and spiritual support”. Palliative care is designed to provide the best quality of life for patients and their families. Hence, it is Soyannwo’s contention that palliative care should be provided by two categories of health and social care professionals. Those providing

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day to day care to patients in their homes and hospitals and those who specialise in palliative care (consultants, clinical nurses, social workers, physiotherapists, chaplains and other religious leaders). The patient feels better, feel supported and have more control over his/her care. Palliative care improves the quality of life for both patient and family. Doctors, nurses and other specialists work together with the patient's other care givers to provide an extra layer of support.

Soyannwo (2004) stresses further that palliative care services in Nigeria are undeveloped. There is continuing resistance to some palliative care concepts including opiate use, the multidisciplinary team approach to the management of medical problems and the inclusion of patient and family as the unit of care. Salako (2009) reports that palliative care services face some challenges in Nigeria, which include: lack of awareness, lack of knowledge and skills set relative to palliative care. The effective palliative care service require more than prescriptions and ingestion of drugs. A synergy of healthcare professionals working cohesively to ensure the physical, social, psychological and spiritual wellbeing of the patient is paramount.

Palliative care requires a multidisciplinary approach to be effective (Blanch, 2002; Holloway, 2003). With different integrated factors which can impact on the psychological and social support, as well as family integration which need to be incorporated in order to achieve effective palliative care services of the terminally ill. Psychological supports are the different behavioural features that are carried out to assist and reduce the distress and agony faced by those with terminal illness. Social support, on the other hand, is an interpersonal process that is context specific and involves exchange of information and perception that the terminally ill is cared for and adequately reassured. The family integrated component to terminal patient care allows the patient not be treated as an individual with problems and symptoms, but also as a family member whose reactions interlock with the support system (Tanchel, 2003). The family of the terminally ill patient is at the centre of the unit of care and their support and education are vital because losses suffered by the patient will be experienced in parallel by the family. Therefore, it is important to give family members opportunities to talk as individuals as well as in groups regarding the palliative care services provided to their loved ones (Davies & Steele, 1995).

Previous researches have looked at the role of palliative care in the era of anti retroviral therapy and vice versa with emphasis on equitable distribution of drugs, its accessibility and affordability. This is only limited to those with HIV/AIDS receiving palliative care and not other terminal illnesses (Oyebola, 2007). Secondly gender issues in palliative care was also reviewed

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with particular emphasis on the plight of women with terminal illness, cultural and community expectation of the roles women play were highlighted and also that most women underplay their symptoms and so do not receive adequate support in order not to disrupt the family (Akeredolu, 2008). Besides, most of these previous studies on palliative care had concentrated efforts on the clinical components of palliative care in Nigerian hospitals, covering such areas as symptom control in palliative care (Soyannwo & Kuye, 2007), palliative care in the 21st century; a tale of four African nation (Onyeka, 2013), palliative care experience in breast and cervical cancer patients in Ibadan (Elumelu, Adenipekun, Soyannwo & Boadu, 2013), and ethical issues in palliative care (Ogundiran, 2007) . Observably, none of these past studies had bothered to focus on the totality of the predisposing factors of palliative care which indicates the combination of psycho-social supports and family integration as determinants of effective palliative care of terminally il; hence the need for this study.

1.2 Statement of the problem

Mankind has always been frightened and in awe of death, even though it is an irreversible end of life everyone would go through. The terminally ill experiences a lot of pain and anxiety which can lead to suffering and threat to quality of life which refers to an individual’s total well-being and includes all emotionally, social and physical aspects of an individual’s life. One major hindrance in rendering palliative care in the Nigerian environment is the taboo of speaking of an impending death. There seems to be a culture of “death denial” among patients, their relatives and health care professionals. Where death is accepted, African prefers natural prolongation of the dying process and want to be at home so that they can make their peace, say farewell, and give final instructions to immediate relatives. As a result of this, many terminally ill keep away from medical treatment for fear of hospitalisation. There is also a form of professional or cultural taboo against open communication about death among physicians. Health care professionals, in many cases, censor the information given to patients in an attempt to protect and prolong the news about the ‘inevitable’. Patients with terminal illness are not given the full picture about their diagnosis and prognosis.

Illnesses remain the major cause of mortality among the human population and it increases enormously in the developing countries. An individual faced with terminal illness is generally unhappy and withdrawn, his psychological well-being is traumatised and this negatively affects his self-esteem, he feels bad with himself due to inability to perform the roles expected of him. The total being is affected, ability to cope with the basic challenges of life

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become traumatised and sees himself at the mercy of other people. Self-efficacy, however, is an individual's ability to be at adequate level of performance that can influence events positively. The terminally ill is not capable of functioning at this optimal level which can be quite depressing.

On few occasions, when patients are educated about their illness and the possible outcomes, some patients have rejected and rebuked the idea. The very nature of the work entails ambivalence and uncertainty, with the result of the intervention less immediate and often intangible. The patient, therefore, is cared for not only as an individual but also as a family member whose reaction interlocks within the support system. This, therefore, raises the salient question: Is palliative treatment necessary when it cannot cure the terminal illness? Considering the cause-effectiveness, is it worth providing palliative care knowing (fully) that death is the end result of terminal illness? Ethically, it is the client's right to have peaceful death, of what importance is psychosocial support and family integration in providing palliative care? It is on this basis that this study investigated the extent to which psychosocial supports and family integration contribute to the palliative care of terminally-ill patients at University College Hospital, Ibadan.

Hence, the study is epitomised on this central issue that: Will the incorporation of the independent variables of diversional support, counselling services, spirituality, rehabilitative supports, financial assistance and life style modification help in improving the palliative care of the terminally ill?

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1.3 Objectives of the Study

The objectives of the study were to:

1) determine the perception of health workers, patients and family care givers on the effectiveness of palliative care services;
2) determine the extent to which psychosocial support and family integration affect to palliative care of terminally ill patients in UCH;
3) examine the relationship between the components of psychological support (diversional support, emotionally support, behavioural support and counselling services) and palliative care of the terminally-ill patients;
4) examine the extent to which social supports (spirituality, rehabilitative services and regular visitation) relate to palliative care of the terminally-ill;

5) assess the relationship between the components of family integration (financial assistance, physical care, life style modification) and palliative care of the patients.

1.4 Research questions

1. What is the perception of health workers, terminally ill patients and family care givers on palliative care of the terminally ill patients?
2. To what extent does psychosocial support and family integration improve palliative care services of the terminally ill patients in UCH?

1.5 Research hypotheses

Ho1: There is no significant relationship between the components of diversional support, counselling services and palliative care of terminally-ill patients in UCH.

Ho2: There is no significant relationship between the components of social support and palliative care of the terminally-ill patients.

Ho3: There is no significant relationship between the components of family integration and palliative care of the terminally-ill patients.

1.6 Significance of the study

For individuals and health care authorities, this study would provide the opportunity to create awareness about health and illness, including the inevitability of death. The inclusion of death and dying education in the educational curriculum would be highly beneficial.

Palliative care improves the quality of life of the terminally ill and also provides opportunity for the patient to benefit from holistic care. So, the study would add value to adult educational research and the society at large in the area of gerontology as the underlying psychosocial support that surrounds palliative care would be brought to the forefront in order to forge a better strategy for the care of those with terminal or life threatening disease condition.

Policy and intervention programme recommended from the study, If adopted, can serve to sensitise stakeholders in palliative care including government, relevant local and international agencies and non-governmental organization. This would address the need for improvement in palliative care practice and subsidise the management of terminally ill in tertiary hospitals, to encourage wider patronage of those with life limiting illnesses.

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1.7 Scope of the study

This study focused on the extent to which psychosocial supports and family integration determined effective palliative care of terminally-ill patients in University College Hospital, Ibadan. This study was delimited to patients with cancer, complicating heart diseases, end stage kidney disorder, HIV/AIDS and neurological problems in radiotherapy ward and clinic, neuroscience wards, medical wards and children's ward. This is because children, also have terminal illnesses and require palliative care too. Diagnosis period is within four weeks of presentation. The terminally-ill patients were drawn from different wards within the University College Hospital which were; Radiotherapy Ward and Clinic, South West Four, East One, West West One, East Two, South East Two, West West Two, West Three, Surgical Outpatients and Medical Outpatients. The clinics and centres are utilised by those that are not on admission but come on outpatient basis for treatment.

The choice of UCH for the study was occasioned by its position as a tertiary health institution with different areas of specialty. The radiotherapy ward and clinic attend to patients with malignant diseases. The palliative care of this group of patients is complimented by the Centre for Palliative Care Nigeria (CPCN) which is the first palliative care centre situated in Nigeria. Patients do visit the centre at regular intervals from their respective homes for psychosocial and spiritual wellbeing.

1.8 Operational Definition of Terms

- **Counselling Services:** This is the professional advice given to the patients with Terminal illness and their family caregivers.
- **Diversional Support:** The support encompasses all forms of activities that can shift the attention of the patients from their distress of diagnosis to other therapies that would relieve their discomfort.
- **Family integration:** It is the involvement and participation of the patient's family in his or her care, which includes financial assistance, physical care, life style modification and role reallocation.
- **Holistic Care:** This refers to the total care that is given as a result of coming together of all health workers, spiritualists and family caregivers in the interest of the terminally-ill patient.
- **Palliative Care:** An approach that improves the quality of life of patients and their families facing the problems associated with life threatening illness.

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- **Palliative Care Services:** This refers to the specialized care offered by the health care team which includes relief of pain, prevention of suffering spiritual care and improved quality of life.
- **Psychological support:** This refers to all the activities given to the terminally-ill aimed at reducing the patients' distress. It includes diversional support, emotional support and counselling support.
- **Quality of life:** Is the terminally ill patient's ability to live a fulfilled life during illness. It involves all activities that would help the person's physical health, psychological wellbeing, adequate level of independence and meaningful life.
- **Social support:** The sum total of all the assistance from significant others that help an individual faced with terminal illness to make him/her function maximally and be part of a supportive social network. Such components include companionship, rehabilitative support, spirituality and regular visitations.
- **Spiritual Wellbeing:** This deals with all the religious aspects of the patients' aimed at raising their hope and increase their faith in the trying period of illness.
- **Patients:** These are sick people that have been diagnosed to have terminal conditions after confirmatory investigations have been done.

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CHAPTER TWO

LITERATURE REVIEW AND THEORETICAL FRAMEWORK

This chapter presents a detailed review of relevant literature pertaining to the study. It was discussed under the following subheadings:

- Palliative care: conceptualisation and issues
- Psychological support and palliative care
- Diversional support and palliative care
- Social support and palliative care
- Spirituality and palliative care
- Rehabilitative support and palliative care
- Family integration in Palliative care
- Financial assistance and palliative care
- Physical care and palliative care
- Centre For palliative care Nigeria
- Empirical studies
- Theoretical framework of the study
- Appraisal of literature
- Hypotheses

2.1 Palliative care: conceptualisation and issues

Palliative care (from Latin 'palliare' to cloak) is a specialized area of healthcare that focuses on relieving and preventing the suffering of patients. Unlike hospice care, palliative medicine is appropriate for patients in all disease stages, including those undergoing treatment for curable illnesses and those living with chronic diseases, as well as patients who are nearing the end of life (Morgan, 2000). Palliative medicine utilizes a multidisciplinary approach to patient care relying on input from physicians, pharmacists, nurses, chaplains, social workers, psychologists, and other allied health professionals in formulating a plan of care to relieve suffering in all areas of a patient's life. This multidisciplinary approach allows the palliative care team to address physical, emotional, spiritual, and social concerns that arise with advanced illness (Regnard & Kindlen, 2001).

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Medications and treatments are said to have a palliative effect if they relieve symptoms without having a curative effect on the underlying disease or cause. This can include treating nausea related to chemotherapy or something as simple as morphine to treat a broken leg or aching related to an influenza (flu) infection (Clark, 2000). Although the concept of palliative care is not new, most physicians have traditionally concentrated on trying to cure patients. Treatments for the alleviation of symptoms were viewed as hazardous and seen as inviting addiction and other unwanted side effects (Seymour, Clark & Winslow, 2004). The focus on a patient's quality of life has increased greatly during the past twenty years. In the United States today, 55% of hospitals with more than 100 beds offer a palliative-care program (Joanne, 2004). A relatively recent development is the concept of a dedicated health care team that is entirely geared towards palliative treatment: a palliative-care team. Palliative care is provided by a team of doctors, nurses, and other specialists who work together with a patient's other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment (Hill, 2007). Non-hospice palliative care is appropriate for anyone with a serious, complex illness, whether they are expected to recover fully, to live with chronic illness for an extended time, or to experience disease progression. In contrast, hospice care is also palliative, the term ‘hospice’ applies to care given to patients with a prognosis of six months or less to live (Jeffrey, 2003).

WHO (2002) defined palliative care as an approach that improves the quality of life of patients facing the problems associated with life threatening illnesses and their families through prevention and relief of suffering by early identification, and relief of pain and other problems be it physical, psychological or spiritual. However, the goal of palliative care is to promote the quality of life across the illness trajectory through the relief of suffering, including care of the dying and bereavement follow-up, Coyle (2002:579) reported the exact words of a palliative care patient:

> *My life’s work is done, but I am not able to die. How can the day to day time I have left be given a sense of meaning?” The hardest thing is living without a goal a new way of being-just being that is the hardest thing: I know that I’m going to die at some point, but I don’t want it to be a painful and undignified death. This is the most important time in my life and yet I feel disconnected from it Its hard to talk to my family about how I feel-they don’t understand.*

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As reflected by the words of the patient quoted, illness both affects and is affected by all aspects of the individual's being, Kearney (2000) opined that the potential for healing in the face of progressive disease is a potential rooted in the special relationship between the healer and the sufferer. The genuine warm and compassionate relationship of a palliative care or hospice care provider, with his or her patient is frequently a healing relationship. The health care team gives attention to the physical, psychological, social, spiritual and existential aspects of the patient and family i.e whole person care (holistic) Morrow (2004) described palliative care as a combination of state of the art clinical competence with fidelity to the patient, the ability to listen and to remain present in the face of much suffering and distress and communication at a deeply personal level with the patient and family. Palliative care involves having a genuine interest in the person as an individual and the ability to convey hope even in the face of death. In the view of Coyle (2002), specialised education and training as well as mentoring by seasoned palliative care team is recognised as a needed foundation for palliative care and hospice care, without such training, health carers inevitably find themselves in situations where they are unable to provide necessary symptom control and amelioration of suffering for those living with advanced progressive disease and those near death.

There is a particular thought that sometimes run through the minds of health care givers which is their inability to adequately care for the terminally-ill due to ignorance, this experience is as true today as it was several decades earlier, it is rather impossible for any health care giver to practise what they do not know, and it's usually traumatic if this thought haunts somebody after the ill person has died. However, when under the care of a skilled palliative care personnel, patients and their families struggling to live in the face of progressive, symptomatic and debilitating disease can be well cared for and supported through this process, and find meaning and peace even in the face of death. This is the essence of skilled palliative care giver-to facilitate the "caring" process through a combination of science, presence, openness, compassion, mindful attention to detail and team work (Brazil, Howell & Bedard, 2005)

In the view of Kuhl (2002), even with the knowledge and art to control the majority of symptoms that occur during the last months, weeks, and days of life, there is much to learn about how to alleviate the psychological and spiritual distress that come with life threatening illness, listening to the experts, the patients and their families will help obtain the necessary knowledge. Kathleen (1998) commented that advances in health care have changed the trajectory of dying, improved nutrition and sanitation, preventive medicine, wide spread vaccination use,

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advancement in appropriate antibiotics and an emphasis on early detection and treatment of disease have resulted in fewer deaths in infancy and childhood, and fewer deaths from acute illness. Majority of deaths occur after a long progressive debilitating illness like cancer, heart disease, kidney disease, lung disease and acquired immunodeficiency syndrome (AIDS). Palliative care needs of children have long been ignored, and in response to this, it has now been expanded by building on the long tradition of hospice care and models of excellent care within the hospice. Palliative care for children represents a special albeit closely related field to adult palliative care. Palliative care for children is defined as the active, total care of the child's body, mind and spirit and also giving support to the family. it begins when illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease, (WHO 1998). Effective palliative care for children also requires a broad multidisciplinary approach that includes the family and makes use of available community resources that can be successfully implemented even if resources are limited, It can be provided in tertiary care facilities, community health centres and even in the children's home.

Morrow (2011) explained that palliative care is a specialised form of care that aims to enhance the quality of life of patients and their families who are faced with serious debilitating illness, it focuses on increasing comfort through prevention and treatment of distressing symptoms, it also focuses on clear communication, advance planning and coordination of care. She further stressed that palliative care encompasses the whole self, caring for the physical, emotional and spiritual needs of patients and their families, the goal is to prevent and relieve these symptoms, thus improving his/her quality of life. Traditional palliative care can be offered anytime in the course of an illness, but ideally should begin at the time of diagnosis.

Morrow (2011) went on to say that it is a common practice to have different doctors treating separate conditions like endocrinologist treating diabetes by managing blood sugar, the cardiologists managing heart disease, nephrologists managing kidney disease. A palliative care physician often acts as the conductor orchestrating the care between several specialist to produce care that is in perfect harmony. Palliative care is carried out by a team of professionals who are committed to working together to provide the patient and her family a comprehensive care, the team includes palliative care physicians, specialist or general practitioners, nurses, social workers, carers, physical occupational speech therapists and spiritualists. The team offers support to patients and their loved ones, helps them navigate through the health care process and assist in making health care choices that are right for them. At present, finding palliative care in an

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outpatient setting proves challenging but that is changing, as more hospice are springing up in developing countries like centre for palliative care (CPCN) in University College Hospital, Ibadan, Nigeria. Someone with any life limiting illness can benefit from palliative care. It was formerly believed that palliative care is only for cancer patients, but it cares for people with different kinds of illness that are life limiting and chronic infections like HIV, heart problems, kidney diseases and neurological disorders (Soyanwo, 2004).

To Dombrowski (2007), palliative care is a new term to many, when it comes to achieving the best quality of life for persons with advanced illness. Palliative care is an approach to health care that focuses on the relief of suffering end of life, seek relief from pain, a sense of control, to relieve family burdens and to strengthen relationships with loved ones, palliative care involves the persons with advanced illness. their family members, in addition to the physician, a nurse, a chaplain, a pharmacist, a social worker, and other appropriate disciplines in group meetings.

The goal is to involve the family in discussions regarding the patient's desires; this may include life prolonging therapy or comfort measures that include hospice care. Due to the fact that most individuals are uncomfortable with a discussion on end of life measures, many seek life-prolonging therapy and then pass away when all options have been exhausted. There is little consideration given to other options like palliative care; this is partly because palliative care is a relatively new concept and also because the families and the person with advanced illness do not want to be seen as giving up. It is, therefore, important to note that a discussion with family members is an obvious decision. Open communication, thus, allows families to become more informed about options for persons with advanced illness. Family members and individuals were thereby encouraged to take advantage of this important educational benefit in order to make the best decision for themselves or a family member in need of help. An obvious complicating factor is that individuals and families hesitate to discuss end of life care because they usually don't know what to say or how to discuss the subject (Tanchel, 2003.

However, palliative care personnel at hospitals serve as intermediaries by introducing information regarding palliative care and the process to family members, usually, just having someone to talk to who has been through the experience is helpful. Many family members are often relieved to have the support of professionals who can guide them to make the best decisions. Palliative care is truly a process that can support individuals and families through the uncharted water of end of life care and decisions. Palliative care models include home-based

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care for those who prefer to be managed at home, anchors specially trained palliative care professionals, maximized coverage and sustainability within modest resources. Hospice is another model of palliative care which can be made up of hospital based unit or suitable accommodation for chronically ill, who would require specialised care and good quality of remaining life (Emilia, 1998; Blanch, 2002).

The palliative care and family centre care provided through hospice programme was essential but the rationing of hospice programme (based on progression) and the requirement of denying life prolonging therapies were barriers that deprived many individuals of the benefit of such care. The palliative care model evolved from the traditional hospice perspective to address quality of life concerns for those patients living for prolonged periods with a progressive debilitating disease. It recognized that such factors required skilled and compassionate palliative care interventions, regardless of prognosis, life prolonging therapy or closeness to death (Ashby, Kissane & Beadle, 1996). Palliative care began in the hospice movement and is now widely used outside of traditional hospice care. Hospices were originally places of rest for travellers in the 4th century (Cooke, 1995). In the 19th century a religious order established hospices for the dying in Ireland and London (Cooke, 1999). The modern hospice which is a relatively recent concept that originated and gained momentum in the United Kingdom after the founding of St. Christopher's Hospice in 1967 was founded by Dame Cicely Saunders, widely regarded as the founder of the modern hospice movement (Cruciatti & Mont, 1995). African hospices provide supportive interventions to their staff, who are exposed to large-scale loss of patients in the HIV/AIDS epidemic (Grahamstown, 2002). The hospice programme at Selian Hospital in Arusha, Tanzania, was begun without resources beyond existing hospital staff and facilities (Hartwig, 2001). In Uganda, Little Hospice Hoima was initiated as a demonstration project of an affordable service at the village level, and Mobile Hospice, Mbarara, offers mobile-home palliative support through roadside clinics (Hospice Africa Uganda, 2003).

From 2005 to date, 23-27 million cases were recorded in sub-Saharan Africa leading to 2.5 million deaths (UNDP, 2010), thus, representing a huge loss which impacts significantly on health systems, social and family structures. In Nigeria, records from the University College Hospital revealed that every year, about 3000 patients attend radiotherapy clinic (Medical Records, 2012) and the statistics has increased by about 25percent within the past five years; out of 190,000 people identified as new cases of tuberculosis in 2011, mortality record was

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about 27,000 and 83percent of the diagnosed cases tested positive to HIV/AIDS, hence the need for effective palliative care cannot be over emphasised.

Looking at the relationship between hospice and palliative care, hospice can best be described as a programme through which palliative care is intensified as an individual moves closer to death. Patients and families living with chronic debilitating and progressive disease receive palliative care throughout the course of illness and its treatment. As they come closer to death, they are able to transition without added distress into hospice programme of care.

In recognition of the changing trajectory of dying, World Health Organization (WHO 2008) modified its definition of palliative care as an approach to care which improves quality of life of patients and their families facing life threatening illness, through the prevention, assessment and treatment of pain and other physical, psychological and spiritual problems (Morrow, 2011). The new WHO definition broadens the scope of palliative care beyond end-of-life care and suggests that such an approach can be integrated with life prolonging therapy and should be enhanced as death draws near. The focus of all these efforts is to change the standard practice of palliative care in which there is a distinct separation between diagnosis, treatment and end of life care to a vision of the future in which there is an appropriate palliative care, for example, at the time of cancer diagnosis and initiation of treatment, the patient would also have access to psychological counselling nutritional services, pain management fatigue management and cancer rehabilitation. According to Cassell (2000), labelling a patient as dying has implication at both individual and social levels. The patient and his/her care may become disengaged, which undermines the potential for growth. The nature of palliative care and the approach of its interdisciplinary team are dependent on the needs of the patients and the resources available. The interdisciplinary team serves as one common denominator. There is flexibility regarding the location of care. It could be in the patient’s home, clinic and hospice.

The term quality of life is used to evaluate the general well-being of individuals and societies; it is used in a wide range of contexts, including fields of international development healthcare and politics. Quality of life should not be confused with the concept of standard of living, which is based primarily on income (Gregory, Derek, Johnston & Geraldine, 2009). Within the field of healthcare, quality of life is often regarded in terms of how it is negatively affected, on an individual level, a debilitating weakness that is not life threatening, life threatening illness that is not terminal (Layard, Richard, 2006; Kahnman & Deaton, 2010). The phrase quality of life means different things to different people, to the health care professional, it

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may mean relieving of suffering; for the relative of the terminally ill, it may mean changing relationships and dynamics within the family, and for the patient, it may be a threat to their . These different views are predicated upon by their individuality and autonomy (Cella, 1992).

There are two components in quality of life which are subjectivity and multidimensionality (Cella, 1992). Subjectivity means that the quality of life can only be determined by the individuals themselves, where the individual is not able to do so, then there must be a good working knowledge of the individual which takes account of all available wishes of that particular individual. It should, however, be borne in mind that the individual's perspective should be the overall goal of the care package focusing on the whole person. multidimensionality aspect of quality of life, entails the physical, functional, emotional and social well-being of the person. Quality of life measures the difference between the person's hopes and expectations against their present position with respect to current experiences (Calman, 1984). He explained further that quality of life is not only about the individual, but the caregiver as well. Caring for an individual may place a heavy responsibility on the shoulders of the carer, thus possibly maintaining the quality of life of one individual at the expense of another. The commonly identified components of quality of life according to Calman (1984) and Frank (2001), includes physical component which entails pain control and symptom management, functional ability that deals with activities of daily living; activity, tolerance, family support emotional stability and spirituality, which means different things to different people. Satisfaction of treatment interventions are necessary and should be what the individual wants, future plans, hopes and wishes, cultural beliefs, perception of body image, sexuality and financial concerns.

Quality of life may be assessed using a variety of measurement tools. The medical quality of life tools tend to measure the presence or absence of symptoms and side effects from treatment. Disease specific tools usually measure physical, psychological and social dimensions of a person's quality of life (Herth, 1990). Whilst this is very important, it should not be assumed that the absence of an unpleasant symptom will mean that the person will perceive their quality of life as being good. All the above mentioned components would vary from person to person as well as fluctuate in respect of the varying magnitude of illness in the different individuals (Scottish Executive, 2001). Since palliative care is an approach that improves the quality of life of patients and their families facing problems associated with life threatening illness, using a holistic approach is a golden approach of care (Fagbenle, 2007). The palliative care team should be well informed of the appropriate approach. While dealing with this, they should show an

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optimistic approach of care and understand that palliative care is a right of every child and adult with a life limiting disease (Fagbenle, 2007). To enhance quality of life, an attitude of partnership between the caring team, the patient and family should be developed i.e politeness, honesty, active listening, explanations, agreeing on priorities and goals, discussion of treatment options and autonomy of the patient. In ensuring quality of life, patient should be pain free at rest and at night. Other symptoms should be controlled as much as possible.

When curative treatment is no longer working for some patients, continued attempts at curative treatment could be harmful, or may provide another few weeks or months of life (though patient may be very ill to enjoy that lease of life) and hope for full recovery gone, the hope for quality of life prevails if the ill person is receiving palliation in hospice or at home with loved ones as well as hope for a dignified pain free death (Quality of Life, 2004).

When patients are given the devastating news that they have a terminal illness, the question that comes to mind is whether they would suffer, and this often becomes the elephant in the room. The patient may not want to ask question because of their fear that no one will be able to answer “No” with any level of assurance. Unfortunately, this may be true – not because of a lack of care, but because so little is known about the age-old human experience, to prevent and relieve suffering, which are important goals in health care (Cassel, 1998; Wright, 2005). Without precision and comprehensiveness, accurately measuring suffering, identifying the most important correlates of suffering, predicting who is at the highest risk of experiencing it, and testing interventions to relieve it, will continue to elude us. Cassel (1998) suggests that these problems can be tied to the reductive methods of gaps. There are some common themes among these definitions. Most often listed are feelings of isolation, presence of unrelieved symptoms and inability to completely capture the experience in everyday language.

In the submission of Barnes, and Nortender (2000), findings from several small studies of terminally ill patients have demonstrated that the prevalence and severity of suffering tend to be high and as noted by Kupelomaki (1998), physical symptoms are often present, but what is so daunting about suffering is that some patients with unrelieved severe physical symptoms report minimal to no suffering, whereas those experiencing minimal physical symptoms may report a great deal of suffering Wright (2005) attributes this to what goes on in everyday clinical care which she labels “medical narrative” in which patients and their families are encouraged to tell only their medical story, which is very circumscribed, and includes the usual pieces of information, medications dosage, past tests and current complaints. What is not always captured

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is the ‘illness narrative in which patients and families tell their stories of suffering and the effects of suffering on themselves, their relationships and ultimately, their world. Without this information, there is little understanding of the source and meaning of the patients suffering.

Reviewing the various ways in which suffering has been characterised in palliative care, Chapman and Garvin (1993) noted three features common to most descriptions. Suffering generally occurs in the context of a perceived threat to the integrity of the self, it is by definition an inherently unpleasant emotional experience, and it represents an enduring psychological state rather than helplessness in the face of threat. In addition to defining suffering, this description provides an understanding of how factors other than physical symptoms can contribute to suffering. Psychological symptoms (e.g depression) and existential distress (e.g concerns about death) also are sources of suffering since they too, can be experienced as unpleasant, can occur on a frequent or chronic basis and can be perceived as uncontrollable (Cassel 1992; Cherny, Coyle & Folye, 1998; Doyle, 2000).

Pain is defined as an unpleasant and emotional experience associated with actual or potential tissue damage (International Association for the Study of Pain, 2004). The Dorland medical dictionary (2002) defines pain as a sensation of discomfort, distress or agony resulting from stimulation of specialised nerve endings. Out of the various symptoms experienced by patients with terminal illness and end of life, pain is one of the commonest and most feared (Paice 2004). Chronic conditions or terminal diseases that cause severe pain can be difficult to manage both medically and psychologically. These painful diseases cause a reduced quality of life for the patient and family members (Halloween, 2008). Pain can interfere with a person’s ability to do daily activities, and essentially enjoy their lives. Palliative care has shown progress in effectively dealing with these types of pain (Koerein, 2004). In the past, palliative care was used for symptom and pain management for the patient; over the last few years, it has grown to be very helpful with the pain and symptoms management of chronic illness. The programme involves nurses, physicians and social workers that are all specialised within this field. These professionals have unique training and are fully prepared in dealing with the issue of hard to control pain (Doyle, 2004).

Palliative care has been able to improve pain management with a wide variety of ailments like lower back pain, rheumatic disorders, neurological disorders and terminal illness. Awareness continues to increase in this programme and patients, having pain difficulty, are adequately referred for proper management. Once the palliative care team takes over the patient, care is

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promptly commenced and the team continues to update the original referring physician. This primary physician often finds a relief from the services of the specialised palliative care team who strives to make the patient more comfortable and this improves their life (Fair Filed Country Business Journal, 2008).

Comprehensive assessment of pain is imperative; this must be conducted, initially, regularly, throughout the treatment, and during any changes in the patient's pain state (Torker, 2005). Assessing patient's pain is a critical part of determining the patient's needs. Without a thorough and accurate assessment, the physician and medical staff will not be able to provide the correct pharmacological relief for the patient. Palliative care helps patients with severe pain by utilising different pain medications with varying strengths to achieve a round the clock pain management (Paice, 2003).

Terminal illness by itself brings about pain to the sufferer; but contrary to general or common belief, pain is not an inevitable part of end of life health conditions, much suffering undergone by patients with terminal illness can be prevented because there are drugs to provide relief. The final goal is to make the patient pain free while maintaining good quality of life as much as possible. The drugs should provide relief for patients and, thus, allow the incurable ill to die with dignity (Akinkoye, 2007). The health care providers are critical members of the palliative care team, particularly in providing pain management. This begins with assessment and continues through the development of a care plan and implementation, the team also provides education and counselling to the patients and their families, thereby making them responsible for developing institutional policies and monitoring outcomes, to provide optimal pain control, all health care professionals, must understand the frequency of pain at the end of life, the barriers that prevent good pain management and the treatment used to provide relief.

2.1.1 Barriers to pain relief: Barriers to good pain relief are numerous and it is due to lack of education, misconceptions or attitudinal issues. These barriers contribute to the large number of patients who do not get adequate pain relief (Baker, 2000). A careful examination of these barriers provides the guide for changing individual practice. The barrier facing individual with other disorders commonly seen in palliative care are not well characterised. These groups of patients are more affected. Barriers in relation to health care providers have to do with fears related to opioids (analgesic), held by professionals resulted in under-use of these analgesic. Survey has revealed that the health care practitioners, including pharmacist express concerns about addiction, tolerance and side effects of these drugs. Despite this evidence, lack of attention

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to pain and its treatment during basic education is frequently cited (Beaver, Luker & Woods 2002). Those providing care at the end of life must evaluate their knowledge and beliefs, including cultural biases, and, as such, educate themselves (Zemosky, 2003). In health care settings, the Opioids analgesic may not be available in desired quantity; this can affect both the sparsely populated rural setting as well as the inner city pharmacies who may be reluctant to carry these medications (Akinkoye, 2003) Pain management continues to be a low priority in some health care settings, reimbursement for these services is poor while some settings lack qualified professionals that have knowledge of pain management. The cost of these drugs may also be an issue (i.e affordability). At the end of life, patient may need to rely on family members or other support person to dispense medication, Paice (2004) discovered that there is little concordance between the patients and family members. The interdisciplinary team in palliative care is essential in providing explanation of the meaning of pain, its possible barriers and good relief. (Clerridge & Cassey, 1998).

2.1.2 Pain in children: The definition of pain recognises that pain is a combined sensory and emotional discomfort, and that a physical manifestation may not need to be present for a child to experience pain (Brown, 2007). Pain varies in types; it can be classified according to duration which may be sudden, persistent, 'off' and 'on', may be associated with physical manifestation. All these ultimately affects quality of life, social activity and personal relationship. Pain could also be associated with mood changes and depression (Paice, 2004). Children are unable to express themselves as adults would. So the palliative care provider should be able to assess them properly- basic tools for assessing them include facial expression, body movement and cry. Brown (2007) emphasised that the assessment of pain should not be generalised but rather individualized as no two persons can be the same and the reaction to pain differs, it should also be borne in mind that improper assessment and its management will have negative impact on the patient's life.

World Health Organization (1998) defined pain ladder as a simple effective ladder for escalation of analgesic drug therapy, devised for pain related to terminal illness.

By the clock-This is to maintain freedom from pain that is every two hours, three hours, four hours or six hours rather than on demand. By the appropriate route- which is to give the drugs through the simplest, most appropriate and less painful route. By the child/patient-the dosage of the pain relieving drugs vary from one child to another, so also the time of administration varies,

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hence the correct dose of the pain reliever is the dose that provides adequate relief of pain with an acceptable degree of side effects.

In relief of pain, the most common analgesics used in terminal illness is the opioid analgesics that belong to the group of narcotics. Although, there are no national prevalence, statistics about pain in Nigeria (Brown, 2007), many of the patients have pain, and this constitutes a major health problem. Effective pain management and control is a very vital facet of palliative care. Poorly managed pain will lead to poor quality of palliative care provided. In many developing countries like Nigeria, the prevalence of pain at the time of terminal illness diagnosis is between fifty percent and seventy-five percent. A terminal cancer patient study in Kenya and UK found that African's main concerns was for pain control and analgesic drugs while for those in developed country, the major concerns was emotional pain (Harding, Powell, Downing & Connor, 2008). Uganda is the only third African country that made morphine available and affordable to its patients population (Spance, Merriman & Binagwaho, 2004). The several challenges facing effective pain relief is similar in other developing nations and this includes drugs availability, lack of referral, fears of misuse, under prescription and lack of public awareness. Cultural and religious beliefs may also constitute barrier (Soyanwo, 2004). Morphine given in increasing amount is safe for the patient's in pain and should be administered until the pain is relieved without producing an overdose as long as the side effects are tolerable. The ideal dose is the one that relieves the pain.

Non-drug therapies, including cognitive behavioural techniques and physical measures can serve as adjunct to analgesics in palliative care setting, though this is not suggesting that when these therapies work, the pain is of psychological origin. Benzeni (2008) reaffirmed that the patients and caregivers abilities to participate must be considered when selecting any of these therapies. This includes their fatigue level, interest, cognitive and other factors. Cognitive behavioural therapies include strategies to improve coping and relaxation. Other aspects of non-pharmacologic measure include education, exercise, coaching, coping music, etc. These have been found to effectively relieve pain-related terminal illness. Cantor (2003) reported suffering from terminal disease. Rhconer (2001), on the other hand, submitted that physical measures like heat and cold massage with cognitive behavioural strategies such as distraction and relaxation were useful remedies in reducing pain among those with terminal illness (though positive response depends on the severity and clinical status of the patient).

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Communication is sharing of ideas or information in order to come to a common understanding. It is a process by which people exchange information or express their thoughts, feelings and attitudes. It is a two way process that involves the transmitting and receiving of messages (Buckman, Baile & Korsch, 1998). It is also the process by which information, meanings and feelings are shared by persons through the exchange of verbal and non-verbal messages (Brooks & Hearth, 1985). For communication to be effective, information should be understood by both the sender and receiver, it can either be verbal or non-verbal, in palliative care practice, improved communication enhances the patient's psychosocial adjustment, decision-making, adherence to treatment, satisfaction with care improved patient understanding and trust. For the palliative care giver, good training in effective communication would improve clinical skills, reduce the high level of stress reported by professionals, reduce burn out, litigation and improve satisfaction.

Communication is an essential element in all areas of life and is more important while dealing with sick people. There is a great need for effective communication while caring from the terminally-ill patient, the family members and caregivers. Good communication in terminal care is believed to enhance the quality of remaining life of a terminally-ill patient and his/her family (Ajayi, 2007). The work of palliative care is based on a relationship with patients, their families, professional team and others. Poor communication on the other hand, makes life difficult for a patient and his family/caregivers. It creates a sense of rejection, confusion, misunderstanding and despair.

There is quite a number of published literatures on the emotional and psychosocial needs of the dying patient, and the importance of communication as a major component of the palliative care delivery (Doyle & Hanks, 1988; Kaplan, Greenfield & Ware, 2001). On the other hand, there is less literature on practical assistance for the palliative care practitioner in improving his or her communication skills (Maguire, 1985). It is evident that in our society, any conversation about death and dying is awkward and different. More so, between the health practitioner and the patient, this is a social problem which originates from the way society view death. Therefore, improving the communication techniques among the palliative care team would make it easier to overcome obstacles emanating from defective communication (Garg & Beckman, 1988).

For effective communication, privacy should be ensured, the environment should be free from all obstacles, communication should be in a relaxed environment, preferably in sitting

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position. If the patient is comfortable lying in bed, he/she should be allowed to do so; radio/television can be turned off with the patient's permission to avoid distractions.

2.1.3 Body language: Try to look relaxed and unhurried (even if one is feeling the opposite), let shoulders relax, feet flat on the floor neutral position adopted and neutral position

Eye contact: Maintain eye contact for most of the time the patient is talking. If the conversation becomes intense or emotionally charged (like crying or angry), it is helpful for the health care giver to look away at that point.

2.1.4 Touching: Touch may be helpful during communication, especially if a non- threatening area is touched e.g hand or forearm. This makes the patient feel comfortable it is likely that touching is comforting during distress and should be encouraged, provided the health care professional is sensitive to the patient's reactions, if the patient is uncomfortable, the health care professional should stop (Older, 1984).

Before commencing communication, the palliative care professional should introduce himself/herself to the patient and let him/her know his/her profession and intention. During dialogue, the health care provider should be attentive and show the patient he is listening and attentive. The listening skills and techniques include open questions (How are you? facilitating pausing or silence when patient speaks, nodding, smiling or telling the patient to tell me more about that") clarifying and handling time and interruptions.

2.1.5 Empathic Response: The nature of palliative care and the outcome of terminal illness calls for empathy in which case the palliative care givers have to be knowledgeable in handling this type of situation. In empathic response, the health care giver does not have to feel sad at the same time that the patient feels sad. This should simply be a technique of acknowledgement, showing the patient that you have observed the emotion he is experiencing. The objective of the empathic response is to demonstrate that the palliative care givers acknowledge what the patient is experiencing. If this is not acknowledged, it renders the rest of the interaction useless (Brooks & Heath, 1985).

The management strategy, therefore, would be for the palliative care giver to assess the patient expectation of his condition, treatment and outcome, it is possible to have a mismatch between what the patient's view is and the medical facts, it is more challenging if there is a marked discordance between the patient's view and reality. The response of the patient too should be assessed, it is important to use the knowledge of communicative skill to identify the

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stage of forming an action plan which could be contemplation, implementation and reinforcement phases to arrive at an action plan.

Bereavement is considered as the socially sanctioned time duration following the death of a significant person that allows for the expression of grief (Johnson, 1977) Society today continues to deny and fear the reality of death, it is suggested that death is swept under the carpet, so that people can distance themselves from a frightening and uncomfortable subject, but it remains a universal fact that 100% of all people will die (Parkes, 1997). Bereavement is not a new phenomenon, rituals and practices marked the change from savagery to barbarism as humans began to illustrate a concern for the dead (Payne 2000). Gender, age and culture can all have different effects on how an individual copes with grief (Jacob 1993; Penson, 2002). By considering these factors and developing an increased knowledge and understanding of bereavement, healthcare professionals can identify individuals who may be at risk of developing complications at an early stage.

Palliative care philosophy has emphasised support for the bereaved as not less important than its other contributions to healthcare in pain and symptom management, home care and family support (Parkes, 1993). Most palliative care teams allocate specific resources of bereavement risk assessment, early intervention, and continued monitoring of individuals exposed to loss of loved ones through terminal illness. Palliative Care Australia has established the maintenance of a bereavement service as a core component of comprehensive palliative care (Palliative Care Australia, 1999). In contemporary society, bereavement, most commonly, refers to the death of a significant person. Bereavement can be expressed in culturally various acts of mourning, for example; funeral ceremonies, or ritualised withdrawal from public activities. ‘Grieving’ refers to the psychological component of bereavement, the feelings evoked by a significant loss, especially the suffering entailed when a loved person dies. Sigmund Freud, (1982) viewed grieving and mourning as the processes whereby the bereaved person adjusts to the reality of their loss, enabling them to disengage from the deceased and reinvest in new relationship (Klass, 1996). John Bowlby’s Attachment theory (1996-80) and Parkes’ Psycho-Social Elaborations (1972) offer psychological models of bereavement, allowing predictions regarding the outcome of an individual’s bereavement process (Parkes, 1993).

Bowlby believed that our emotional bonds ‘arise out of deep seated innate mechanisms which have evolved in order to ensure survival’ (Parkes, 1993). Bowlby argued that infants of many species have physical features and behaviours which offer care and protection from older

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group members. Infants also possess a motivational “attachment system” designed by natural selection to regulate and maintain proximity between infants and their caregivers’ (Fraley & Shaver, 1999). The theory implies a cause-effect relationships between early attachment patterns and later reactions to bereavement, arguing that ‘whether an individual exhibits a healthy or problematic pattern of grief following separation depends on the way his or her attachment system has become organized over the course of development’ (Fraley & Shaver, 1999:740). While accepting Bowlby’s theory, Parkes also emphasises the importance of the psycho-social transitions required after bereavement. These depend upon the role the deceased had in the life of the bereaved (Parkes, 1993).

Kubler-Ross (1969) models of grief and coming to terms with death have also predominated. She suggests five distinct phases: denial and isolation, anger, bargaining, depression, and finally, acceptance (Kubler-Ross, 1969). Any person who is bereaved, facing their own death, or dealing with loss, should move through these phases sequentially. Potentially, a person could get ‘stuck’ at any stage, impeding their movement to the next stage and, thus, obstructing ‘resolution’ of their grieving process.

Caring for individuals and their families prior to and following the death of relatives or friends can be very stressful for healthcare professionals and can cause them to question their beliefs and attitudes. The importance of relationships and attachment in understanding how individuals experience bereavement was further developed by Bowlby (1980) who proposed that attachments are formed early in life between the child and the parents in order to feel safe and secure, and to survive. However, if this attachment is threatened, it can lead to intense anxiety, despair and emotional detachment e.g. children who had lost something special might cry, shout and have tantrums so that it is brought back. Bowlby claimed that in adult life the same mechanism are used to attempt to bring back their loss (Payne, Horn & Relf, 2000). His four-phase model of grief includes: shock and numbness, yearning and searching, disorganization, despair and reorganization. Bowlby firmly believed that if the phases of grief were worked through, the risk of complicated grief would be lessened for each individual, as safety and security was reintroduced into their lives (Payne, 2000; Evans, 1994).

Practical advice is commonly sought by family and friends, but also by staff who have supported patients through stages of discomfort, fear and regret. There are no quick and easy answer, no recipes for every situation of loss and grief. Nevertheless, many useful texts are available, Worden (1991) and recent reviews by Parkes (1998) and Sheldon (1998) are succinct

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and helpful. Worden (1991) suggests that a bereaved person needs to accomplish four basic tasks: accept the reality of the loss, experience the pain of grief, adjust to an environment from which the deceased is missing; and reinvest energy in other possibilities. One of the most effective ways of managing a bereaved person is to offer a safe and caring setting in which to express grief, facilitated by someone who is not too close to the bereaved or the deceased person, and so not seen as required to share the burden personally (Worden 1999). Such a setting is provided by a bereavement group, whose members have all experienced loss and who meet with a trained facilitator to share their experiences and feelings. Members of the group find support in these encounters through mutual understanding (Mckissock, 1994). Maintaining contact with the bereaved person is also important, whether it be in the form of a friendly telephone call from a volunteer or more skilled counsel from a social worker or trained bereavement worker. Parkes (1980). Regular anniversary remembrances (such as a card or phone call) from the team are considered helpful by many, gently breaking in on the difficulty or loneliness. The opportunity to attend memorial service, some months after the death has occurred, offers a focus to the hope for healing process.

It is important to recognise that, along with the sadness, anger, bewilderment and anxiety that can accompany loss, natural healing processes are often also at work to facilitate adjustment and adaptation. Separation from people and environments that are important to an individual, occurs repeatedly throughout life. The ensuing sequence of events often entails disbelief or denial, followed by intense physical reactions of weeping and yearning. This may be succeeded by a time of extreme loneliness and disturbed thought, with repeated replaying of the sad events. Only after a longer period will a sense of reintegration and readjustment allow the bereaved person to take up life again with confidence. But there is no set or certain sequence to follow, and emotions may fluctuate wildly, while sometimes flaring up with an intensity of emotional pain may elongate the initially promised adjustment period. (Parkes, 1980)

The grieving process may be complicated for certain vulnerable individuals or for any person faced with especially stressful circumstances of loss. People who have suffered earlier separation or losses for which adjustment proved difficult, people with existing psychiatric disorders, or people coping with family dysfunction or uncertainty in their close relationships will often experience greater difficulty. The loss of close relatives or friends (e.g, a spouse or one’s own child), a sudden traumatic death of suicide, death by murder or from a disease is difficult to talk about (eg, AIDS) can also complicate grieving (Walshe, 1997; Raphael, 1999).

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These situations may increase the risk of intense and prolonged mourning, depressive or anxiety disorder and poor physical health. Skilled assistance is often needed to help people in these situations progress beyond their grief.

Major cultural factors also influence how grief is expressed and managed. People from some culture express their grief loudly and publicly, while others become silent and withdraw. It is important to respect “cultural safety” and meet with families and individuals on their own cultural terms. (Prior 1999). Particular importance is attached also to grief affecting adolescents and children, which requires a sensitive recognition of their special needs (Henshelwood, 1997; Stokes, 1999). Many palliative care workers who are experienced in bereavement care are concerned at the lack of bereavement support available in major healthcare institutions such as teaching hospitals. In such environments, sudden death, traumatic death and death in unfamiliar and isolated circumstances creates, more likely, the risk of complicated grief for those left behind. This deficiency is being particularly addressed in palliative care (Williams, 2000).

Grieving is a normal response to loss, and not everyone needs expert intervention to help manage grief. Assessment by palliative care services can help determine who needs assistance and recommend appropriate responses. If considered appropriate, intervention should begin at the time of referral and continue through terminal care into the time after death. That means a focused and structured program within the day-to-day work of the palliative care team, calling for resources that have not always been easy to access or maintain. (Aranda, 2000). Grief is an emotional state which has physical and psychological dimensions, and is associated with the awareness of either imminent or actual loss of a significant person (Udoh, 2000). The grief that occurs before death is generally referred to as anticipatory grief. This is well demonstrated in the significant relative (son or daughter) of a patient with terminal illness whose death was prolonged for two to three years. During these periods, the son has experienced grief and had actually worked through his grief during the period of the patient’s agony while awaiting the inevitable end, so the son’s feelings of guilt and anger had been reduced by the unrelented care he offered the patient.

Grief process, according to White and Gathman (1973), are divided into three stages. The first stage is manifested by Shock, disbelief, numbness, weeping and wailing with general agitation. This stage of grief is similar to denial and anger stages as classified by Kubler-Ross, this begins immediately after the death event and may last three to four days. In the second stage of grief, the survivor longs for the dead, recalls the happy memories shared and has visual

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images of the dead. He is filled with sadness, unable to sleep, irritable and restless. This commences shortly after death and the maximum impact becomes obvious about the fourth week to three months after the death of the significant person. The period can persist for a year or more, the survivor exhibits a period of bargaining for the restoration of the deceased to life. The third stage is the grief resolution phase which occurs a year or more after the death of that person. It is similar to the acceptance stage in which the survivor is able to resume to ordinary life activities, to recall the past and the deceased without pain and to establish new relationships with others.

2.2 Psychological support and palliative care

Psychological support is all forms of activities carried out to reduce the distress associated with burden of terminal illness, including the emotional aspect of care related to the illness. This type of support relates to the mind and involves some degree of mental activity which can be classified as an intellectual process (Farlex Clipart Collection, 2003). The National Council for hospice and specialist palliative care service (1997) has defined psychosocial care as the emotional and psychological well-being of the patient and their family/carers including issues of self-esteem, insight into an adaptation to the illness and its consequences, communication, social functioning and relationship. The council explained that psychosocial care addresses the psychological experiences of loss and facing deaths for the patient and their impact on those close to them. It involves spiritual beliefs, culture and values of those concerned and the social factors that influence the experience.

Psychological support is the process of meeting a person's emotional, mental and spiritual needs, which are the essential elements of positive human development. Psychosocial support is needed by all in order to promote their psychological and emotional well-being as well as physical and mental development (Health link Worldwide, 2006). Psychological support helps to build resiliency in both adult and children faced with life threatening/life limiting conditions. It supports families to provide for the physical, economic, educational, social and health needs of their loved ones (Hearn, Lakes & Young, 2008). This, however, helps to build internal and external resources for them and their families. This makes them able to understand and deal with adverse events (Sheldon, 1997).

Additional psychological support can also be given by caregivers which serves to complement the ongoing support from families and communities. Psychological support is very

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vital in the effective management of the terminally-ill (Burotta, 2010). Many things can have impact on a patient's psychosocial well-being, including poverty, conflict, neglect and abuse. Diseases like HIV/AIDS with cancer can compound these problems. As a result, they might experience traumatic events such as the illness and death of parent, violence, stigma, discrimination isolation and loneliness. Where psychosocial support is appropriate, it helps the patients and their families to provide for the full range of their needs (Monroe, 2000). This type of support should be part of comprehensive programming; it cannot be a stand alone service. The interventions should include a variety of approaches such as counselling, family therapy, memory work and succession planning (Isabelle, 2009).

Psychological support at the end of life is a difficult time for patients and their relations and carers. It is important that psychological care be provided to palliative care patients and their families in various ways through a range of medical nursing and allied health care professionals. Psychosocial support is needed for patients with terminal illness requiring palliative care. These illnesses include advanced cancer, end stage kidney diseases, heart failure, complicated lung disease and progressive neurological disorder (multiple sclerosis). WHO (2002) defines palliative care as the active total care of patient whose disease is not responsive to curative treatment control of pain and other symptoms, be it psychological, social and spiritual. The goal of palliative care, thus, includes:

- Relief from pain and other distressing symptoms.
- Affirms life and regard dying as a normal process.
- Neither hastens nor postpone death.
- Integrates the psychological and spiritual aspect of patient's care.
- Offers a support system to help the family cope during the patient's illness and in their own bereavement.
- Uses a team approach to address the needs of patients and their families, including the bereavement counselling if indicated.
- Enhances quality of life and may also positively influence the course of illness.
- Applicable early in the course of illness with other therapies that are intended to prolong life.

The diagnosis may provide a range of emotional responses in the patient or family member which could involve fear of physical deterioration/dying pain/suffering, loosing independence from the consequences of illness or death of loved ones, anger at what has happened or what may

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have caused such to happen, unsuccessful treatment, sadness at approaching the end of life, restriction of activities due to illness, guilt/regret for actions in some cases for contributing to the development of the illness, changes in sense of identity, adjusting to thinking of themselves as unwell, dependent on others for existence (Lloyd & Williams, 2008). Loss of self- confidence, sometimes related to loss of physical functioning/changes in appearance, confusion about what has happened, the future and choice available. Most terminally-ill patients develop psychological and psychiatric symptoms during the terminal phase of illness, either alone or in combination with physical symptoms (Miller & Walsh, 1996; Kasser, Malt & Hagen, 1998). Among many possible psychological and psychiatric complications, the most common are anxiety disorders, depressive disorders and cognitive disorders which can be major sources of suffering for patients and can pose significant management problems both at home and in institutional settings.

The recognition of anxiety in the person with terminal illness can be challenging. Individuals who are anxious may present with a variety of symptoms, including subjective feelings of tension, apprehension and worry as well as overt signs of restlessness, hyperactivity, hypervigilance, sleeplessness, tingling and numbness physical manifestations of anxiety often which overshadow psychological or cognitive ones in patients with terminal or advanced illness (Holland, 1998). Anxiety can also arise from medical complications of illness or uncontrolled pain. In the dying patient, anxiety also may reflect impending heart attack or respiratory dysfunction or dehydration. Anxiety in terminal illness commonly results from medical complications, other considerations include the contribution of anxiety to non-compliance with medical care, family and staff reactions to the patient's distress and the balance between the risk and benefits of treatment. The management of anxiety in terminal illness also involves the use of appropriate medications (Holland & Massive, 1989).

The health care team relies on the presence of cognitive symptoms which includes feelings of worthlessness and hopelessness, excessive guilt and suicidal thoughts. For the professional to interpret feelings of hopelessness in the terminally-ill which may become an issue when there seems to be no hope for cure or recovery, this hopelessness and a sense of despair could be the cause of a depressive disorder. Knowledge of the disease condition and even the potent chemotherapeutic agents with their antecedent reactions poses a major predisposing factor for depression (Massie & Holland, 1990; Donnelly & Lynch 1995). To relief the terminally-ill of this depression, the clinician would manage him/her with a rapid acting psychostimulant while

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the very ill that is close to death will most likely benefit from mild sleeping medications with pain relieving drugs given by infusion (Billings & Breitbart, 1995).

2.3 Diversional support and palliative care

This encompasses all forms of activities that can be used to turn the attention of the terminally-ill from the distressing state of his/her condition. Chochinov and Breitbart (2000) identified specific diversional intervention in palliative care which are psychological support, psychotherapy, behavioural cognitive therapies and educational therapies. The psychological therapies are used increasingly in palliative care, such as cognitive and behavioural therapies, adapted from the terminally-ill suffering from anxiety, depression or stress. These therapies explore the existing coping strategies and facilitate the development of new and effective strategies so that the patient can regain a sense of control. Guided/Imagery is another technique used to aid relaxation (Heaney, 1992), while others have used patient narrative to encourage reminiscence and to encourage a holistic approach by gaining insight into the patient's world. The specialist social workers in palliative care are involved in a range of intervention measures involving patients, families, carers and the local community.

Ashby (2007) explained that it is helpful to differentiate between therapies which patients believe might cure them and those that help them to live comfortably with their disease. Positive thinking strategies which obstruct appropriate care delivery may also need to be addressed skillfully. Psychosocial and Palliative Care Program Options Moffitt Centre is committed to providing patient with comprehensive palliative care from the time of diagnosis of terminal illness, throughout course of illness to the end, the diversional support and palliative care programme consists of a multidisciplinary team comprising neurologists, neuropsychologists and social workers that can provide pain management, individual and family counselling consultation and advocacy services. The neuropsychologist conducts comprehensive evaluation of cognitive and behavioural function using standardized tests and procedures. Regnard & Kindlen (2001) explained further that a diagnosis of terminal illness and the challenge that a treatment regimen present can understandably lead to distress for the patient as well as family members and friends. The palliative care team are available within every programme to assess each person and family's situation, which recommends effective ways of managing distress and other emotional and practical consequence of the illness.

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Living with a terminal illness poses many challenges for patient and families. Professionally led support groups can provide a safe and affirming environment in which to learn alternative methods of coping, obtain information about the illness and its treatment, gain problem-solving skills, practise communication and alleviate feelings of isolation. For examples recognising the psychosocial aspect of breast cancer is one of the strengths of such programs. The support group, FACT (Fight against Cancer Together) was founded by those with such ailment and the group continues to provide both local and regional education for those within the group. Hospitalization and treatment of some terminal illness as highlighted in the submission of Sheldon (1997) may require follow up care at home or in a rehabilitation setting like hospice for optimal recovery. Some form of treatment may also be given at home to reduce the length of hospital admission. A clinical social worker and case manager work together to ensure the plans of care throughout the treatment period with proper coordination with the medical team. The social worker also helps to make arrangement for lodging in case the patient and family do not have an accommodation within the treatment area. All these coordinated efforts of the multidisciplinary team will enhance diversional support strategies for the terminally-ill.

2.4 Counselling services and palliative care

Counselling is a health advice and opinion. It is more than a solution to an immediate problem. Suggestions are essential features in effective palliative care management of the terminally-ill. This actually should be an integral part of care in order to help the patient and family to have up-to-date information about the illness and the best way to forge ahead in the face of uncertainty (Babalola, 2007). Counselling plays a vital role in palliative care practice as it is a confidential discussion between the patient and their care provider. The terminally-ill requires counselling on every step of his mode of management to be able to make informed choices and decision related to his health. The significant family member could only be involved if the patient requests for such or if the person is very ill, nearing death or unable to communicate. This type of counselling is issue centred and goal directed and takes place in form of a dialogue which helps to provide options to clients for decision-making and behaviour change.

Fagbenle (2006) stressed further that it should be focused on immediate pressing problem of the terminally-ill and thus encompasses area related to the feelings and emotions of the counsellee. The type of counselling varies according to the diseased condition of the client and,

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as such, a good counsellor has to be knowledgeable and have up to date information about the client’s condition. A good counsellor has to be empathic, non-judgemental, reliable and trustworthy. Onyeka (2010) identified the need for a good counsellor to be cheerful and polite, should be a good listener and be very observant. The nature of terminal illness, receiving palliative care requires reliability from the multidisciplinary team and the principle of confidentiality is important as whatever is discussed remain between the patient and the counsellor. All patient information should be kept private and is only shared among other health workers involved in the care only on a “need to know” basis. All medical records and registers are kept secured.

Babalola (2007) explained the uniqueness of counselling during terminal illness that it should centre around giving psychological support for the client, and should provide culturally sensitive interventions. It requires paying attention to psychological reactions of client and lastly open discussion about death could be necessitated especially if the client is nearing end of life. The social-cultural context need to be borne in mind during counselling as they need to realize that culture and tradition have great impact on people’s attitude, ideas about illness and death. The counsellor therefore needs to be sensitive to cultural differences and respect them. The following are common features to all types of counselling: the time should be appropriate and adequate for effective transfer of information and behaviour modification, counselling session should not be rushed or unnecessarily prolonged, but should allow for good rapport and trust. The accessibility of care should be convenient both for the terminally -ill and other care givers. Arrangement can also be made for home visit if such is indicated and the counsellor should be available (even through phone numbers) the health care team should appreciate the stress caused by fear of being diagnosed with terminal illness, should the patient become hostile and aggressive, the care provider should accept the consequent emotions and reactions of clients and that of their relations. Trust is an essential element of counsellor-client relationship which is built on the understanding that whatever is discussed remains confidential between them.

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2.5 Social support and palliative care

Social support is the perception and actuality that one is cared for, has assistance available from other people and that one is part of a supportive social network. These supportive resources can be emotional, tangible, informational or companionship in nature (Wills & Clark; 1995). Social support has a complex effect on the individual, but it is calming and positive. It may, however, change one's assessment of the stressful event or prevent the individual from engaging in damaging behavioural responses.

Taylor (2011) viewed that social support can be measured as the perception that one has assistance available, the actual received assistance or the degree to which a terminally-ill person is integrated in a social network. Support can come from many sources such as family, friends, pets, organisations and co-workers, etc. The need for social support of patient with terminal illness remains pivotal for the palliative care practitioner (Ashby, Rissane & Beadle 1998). Attending to the social needs of the terminally-ill and those of their family is an integral part of caring in accordance with palliative care approach. Social care/support is specifically concerned with the mental and emotional well-being of the patient and their family carers including issues of self esteem, self efficacy, insight into and adaption to the illness and its consequences, communication social functioning and relationship (Dix & Glickman, 2002). The Council for hospice and Specialist Palliative Care (2000) emphasised the importance of social care in palliative care and reported that "The social fabric of their lives is central to how they make sense of their illness experience, the meaning they draw upon to understand these and the range of resource they can call upon to help them manage them". In practice, the social aspects of palliative care are often limited to a focus upon the patient's family ignoring community influences. The terminally-ill may feel a sense of loss of control, fear or anger. Their relatives too may be experiencing these emotions and the sad consequence is that these often cause a gap between them.

Clark (2002) stated that the challenge facing palliative care is how to reconcile the high expectations of technical expertise which calls for a humanistic and ethical orientation to the care. There is a concern to understand what best practice is, and what the experience is like for the patient, the carer and professional. Psychosocial aspects of palliative care have to be the concern of all the team because all the elements, comprising total pain require attention if suffering is to be relieved and quality of life improved. In psychosocial assessments, the health care professional needs to assess individual strengths, coping styles and experience which would vary from one person to the other. The time invested in this initial assessment is not wasted, but rather build a firm foundation for the patient professional-partnership. The initial assessment may indicate the need for more formal psychological or social assessment. Monroe (1998) stressed the need to maintain autonomy which includes respect for dignity and the opportunity to exercise choice and support. Jeffrey (2003) also emphasised the need to assess the ways in which

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the illness has changed the life of the individual, this will identify any unfinished business, the impact of the disease on their relationship and concepts of body image may identify psychosexual issues that need to be addressed, the assessment should also include the meaning of the illness to the patient and his family, his hopes and fears for the future. Morgan (2000) revealed that psychosocial issues involve the understanding of the ethnic, cultural and religious background of the terminally-ill and also the potential impact of these influences on the individual and their families/carers. All these should be based on an understanding of loss and change, family dynamics counselling and knowledge of social policy and resource.

It is important for the social needs of the patient and carers to be assessed, so that appropriate levels of support and treatment can be offered. A social approach is a patient and family-centered approach, and is vitally important as it represents a mechanism for retaining the holistic approach of modern palliative care. Social care can restore many of the original value and vision of palliative care to a specialty threatened by increasing medical technology. Clark (2002) opined that modern palliative care has persuaded doctors to be gentler in their acceptance of death. The influence of advancing medical technology has led to the adoption of futile treatment and an assumption in society that every cause of death, can be resisted, postponed or avoided. Advocacy is an important attribute of social support. Providers of this support serve as advocates by motivating and empowering recipients to act on their behalf. Reassurance, reinforcement, affirmation and encouragement are common advocative strategies that can be employed in an atmosphere of unconditional positive regard and caring (Tichon & Sapiro 2003). The initial social support given to the terminally-ill will help to improve his/her wellbeing; it boosts the immune system as well, thus, helps in preventing psychological depression (as a result of terminal illness). According to Weber (1998), the kind of social support can be further classified into multiple types, namely, informational support, emotional support, appraisal support and instrumental support – informing an individual of the typical course of illness provides support through information given, expressing care and affections for someone provides emotional support, providing evaluation about a person’s ability to achieve a goal is appraisal support providing material resource such as food or money to assist someone is instrumental support.

Jutilee and Khan (2007) submitted that social support and social network show positive effect on health and wellbeing of people required at every stage of life. Researchers commonly make a distinction between perceived and received support. Perceived support refers to a

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recipient's subjective judgement that providers will offer (or have offered) effective help during times of need while received support refers to specific supportive action (advice/reassurance) offered by health care providers during time of need (Ucheno, 2004). Furthermore, social support can be measured in terms of structural support or functional support. Structural support (social integration) refers to the events to which a recipient is connected with a social network like the number of social ties or how integrated a person is within his or her social network, family relationships, friends and membership in clubs and organisations contribute to social integration. Functional support looks at the specific functions that members in this social network can provide. The different types of social support have different correlations with health and personal relationship (Cantor-Grace 2007).

Bolen (1999) and Canto-Grace (2007) explained further that social support can come from a variety of source including (though not limited) family, friend, romantic partner, pets, community ties and co-workers. Source of support can be natural (i.e. family and friends) formal (mental health specialist or community organizations support from a romantic partner is associated with health benefit, particularly for man). Early familial social support has been shown to be important in children's ability to develop social competencies and support parental relationship.

2.6 Spirituality and palliative care

Spirituality is culled from latin word "spiritualitas". It can be defined as whomever or whatever gives one a transcendent meaning in life. It is often expressed as religion or relationship with God, but can also refer to other things, nature energy, force, belief in the good of all, belief in the importance of family and community. The spirit is the essence of the person (Puchaiski, 1999). The spiritual part of each person can bring wholeness to the emotional, physical and intellectual parts of life. One's beliefs and values can profoundly affect how a person copes with illness and with the management of illness. Hence, spirituality is important during all phases of health and illness, though spiritual and religious factors play an especially prominent role in a patient's experience with terminal illness, the dying process and death (Macgans 1999).

2.6.1 Characteristic features of spirituality

- Personalized system of beliefs.

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- Broad term with varied definition related to issues of meaning hope, purchase relationship and seeking answer to universal questions of life and death.
- One’s search for meaning.
- One’s faith system (everyone has a faith system, atheism also constitute a kind of faith system).
- Personal system of beliefs that give order and meaning to life.
- Based on the unseen and the unknown.
- One’s relationship to his/her supreme being.
- May be religious or philosophical expressed or unexpressed.
- Individualised, personal, experiential and dynamic.
- Spirituality is free and open.
- Religion and spirituality are not the same, but are overlapping concepts.
- Some people who see themselves as spiritual do not formally endorse a religion.
- Some people who are religious are not spiritual.

In palliative care, the carer should ask himself what gives meaning to life. This could be friends, carer, family, nature, ant animals, music, a higher power. Ask the patient what gives meaning to his life and also recognise what gives meaning to their lives. All these meanings should be included in the plan of care. In illness, a lot of questions come to mind which include why is this happening to me? How will I be remembered? How can I be forgiven? It should be acknowledged that there may not be concrete answers to these questions but must understand that the question itself is an expression of patient grief.

Saunders (1967), the founder of the hospice movement describes the intense suffering by dying patients and their family members as “total pain”, including physical, social, psychological and spiritual pain (all are interactive). Spiritual pain, thus includes, loss of meaning, loss of hope, loss of identity due to lost roles, lost activity and lost independence, anger of God, sense of betrayal, abandonment by God, disruption in one’s faith system, fear of God or punishment and need for reconciliation/forgiveness. Spiritual healing as well as psychological and emotional healing can happen even when physical cure is not possible. Openness to spiritual healing will often be shaped by one’s image of or experience of God. Personal thoughts and forgiveness, religion can also aid spiritual healing by supporting communities of faith, offering ways to concretise spirituality and offering responses to universal questions. Bolen (1996) addressing unfinished business, particularly reconciliation with God family, friends and others is still part of

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spiritual healing. Opening gradually to a large understanding of life can assist individuals to perceive healing even in death.

Usually, when nearing the end of life in palliative care, spiritual concerns have to be included in treatment plan. For example, a chaplain should be consulted, recommendation for meditation and relaxation will be necessitated; the belief system of the patient must be respected. The carers must be sensitive to the patient's specific religious beliefs and needs around the experience of suffering and death. Assess to spiritual resources should be provided and this entails referring to the hospital chaplain, the hospice chaplain, the patient's parish priest, minister, Rabbi or Imam (Weissman, 2007).

Religion and spirituality are among the most important cultural factors that give structure and meaning to human values, behaviour and experiences (Lukoff, Lu & Turners, 1995 as cited by Mueller Plevak & Rummans, 2001). For patients at end of life, spiritual and religious concerns may be stirred, or made stronger, they may question their faith or examine it more in depth. Puchaiski (2007) opined that spirituality is important during all phases of one's health and illness, but spiritual and religious factors play an especially prominent role in a patient's process and death. He went further to explain that "illness is both soul shaking and social evoking for the patient and for the significant others, to whom the patient matters, innocence is lost, vulnerability becomes inevitable and the person is no longer who he was before the onset of illness and will never be the same". According to Ambuel (2001), during times of illness and crisis, people may find that their spiritual needs increase, the terminally-ill patients and their families get strength and hope from spirituality, which is an ongoing issue – a part of the patient's journey not, something to be addressed at the last minute. Paying attention to spiritual needs can contribute to an increased quality of life (Bolen, 1996). Reviewing the aspect of religion, its features were as follows:

- Religion derived from the word "religion" meaning to bind together.
- More structured belief system that addresses universal spiritual questions.
- Provide a framework for making sense of the meaning of existence.
- Religion rites and rituals provide a concrete way of expressing spirituality.
- Most religions expect general adherence to a particular body of beliefs (doctrines) regarding one's relationship with God.
- Corporate (group based) structured and organized.

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These psychological concerns also overlap with spiritual anxiety. These might be fears about what happened after death or existential question about the meaning of life. This is common when someone is facing the end of their life or of someone close to them (Williams, 2006 as cited in Lloyd Williams, 2008). However, the patients illness may have a number of social consequences for themselves and those close to them (Sheldon & Monroe, 1999; Hearn, 2008; Lloyd & Williams, 2008). The illness may have impact on the patient's ability to perform everyday social task (i.e activities of daily living which includes shopping, cleaning laundry, paying bills etc). The illness may render the patient unable to perform previous social roles such as parenting, caring for a sick/elderly relative or maintaining paid employment. Spirituality has a significant bearing on hope, and this applies to both adult and young who experience terminal illness. Hope is intimately bound with loss and suffering. As Marcel (1998) observed, "hope is situated within the framework of the trial". It is the paradox that manifests itself so fully at the end of life. In the view of Ersek and Cotter (1999) the critical role that hope plays in human life takes on special meaning as death nears. The ability to hope is often challenged, and it can include patient and families during terminal illness. Hope for a cure is almost certainly destroyed. Many patient's and families experience multiple losses as they continue an illness trajectory that is marked by increasing disability and pain. Even when hope appears to be strong within the dying person, it can be problematic. Hopefulness is perceived to be based on unrealistic ideas about the future. Important issues may be left unresolved as individuals continue to deny the reality of impending death. Hope is an important concept for many disciplines including philosophy, theology, psychology nursing and medicine (Farran, Herth & Popovich 1995).

Dufault (2001) also theorised that hope has two interrelated spheres, particularized and generalized. Particularized hope is centred and depended on specific, valued goals or hope objects. An example is the hope of a terminally-ill patient to live long enough to celebrate a particular event. In contrast, generalized hope is a broader, non-specific sense of a more positive future that is not directly related to a particular goal or desire. Dufault likened this sphere to an umbrella that creates a diffuse positive glow on life. Dufault (2000) postulated six dimensions of hope which are affective, spiritual, relational, cognitive, behavioural and contextual. The affective dimension of hope encompass a myriad of emotions, hope is accompanied by many positive feelings including joy, confidence, strength and excitement. The full experience of hope, however, includes uncertainty, fear, anger, suffering and sometimes despairs. Marcel (1998)

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argued that in its fullest sense, hope could only follow an experience of suffering or trial, Marcel's thesis is corroborated by the experience described by people with terminal illness who see their disease as a "wake-up call'' that has opened their eyes to a greater appreciation for life, and an opportunity for self-growth.In other words, it is an event that has forced them to confront their mortality while also inspiring hope. The spiritual dimension is a central component of hope (Herth & Gibson, 2003).

Hopefulness is associated with spiritual wellbeing. These activities include religious beliefs and rituals but extend to broader conceptualization of spirituality that encompass meaning and purpose in life. Serious illness and suffering can challenge one's belief and trust in a benevolent deity or be viewed as punishment from God, either interpretation of suffering can result in hopelessness. Relationships with significant others is another important dimension of hope. Hope levels are positively associated with social support (Johnson & Harris, 2001; Ebright, 2002) reported that the HIV peer-counselling relationship inspired hope, despite being vital sources of hope, others can threaten the terminally-ill by distancing themselves from him/her showing disrespect, regarding the patient's experience, disclosing negative information or withholding information.

The cognitive dimension of hope encompass many intellectual strategies particularly those involving specific goals that require planning and effort to attain. If one repeatedly fails to attain valued goals, hopelessness and passivity can result. The behavioural hope is strongly associated with coping. Hope has been identified as a foundation or mediator for successful coping. Activities that foster hope are similar to the problem focused coping strategies originally described by Lazarus and folkman (1984). Strategies to maintain hope include problem-focused coping method (e.g setting goals actively and getting one's affairs in order) and emotion focused strategies i.e using distraction techniques, appraising the illness in non-threatening ways. Contextual dimensions of hope, however, are life circumstances and abilities that influence hope. This includes physical health, financial stability, functional and cognitive abilities. Common threat to hope as postulated by Harwood (2002) and Evangelista (2003) are acute, chronic and terminal illness, cognitive decline, fatigue, pain and impaired functional status. These invariably decrease hope, if people are able to overcome the threat through cognitive, spiritual, relational or other strategies.

Children are also faced with terminal illness; the commonest of this illness is cancer which can affect any part of body. When this happens, spiritual care is also paramount within

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which hope is embedded. In an early study, Stern, Wright and Shontz (2010) study hope in children with chronic disabilities, and in the significant adults in their lives (e.g., parent, teachers, and physical therapists). Both the children and the adults were interviewed, allowing for the identification of differences between the two samples. The investigator found that hope for the children in their study was two-dimensional which involved an awareness of the positive and a sense of time orientation. For younger children, hope was present-focused, whereas hope in older children, had a future orientation. Younger children also saw adults as being in control of a situation, and were less concerned about assessing how realistic their particular hopes were. In contrast, adults actively assessed the realities of the present and possibilities for the future. Artinian (1984) explored hope in older children, aged 10 to 20 years, who underwent bone marrow transplantation. The finding suggested that ways to reduce stress and instil hope among younger patient and their parents include managing physical discomforts, making children and parents feel cared for, being non-judgemental when children and parents vent anger, preventing boredom, and assisting with making and altering plans. A programme of research by Hinds and colloquies (1999) elucidated the experience of hoping in adolescent.

Hinds defined adolescent hopefulness as possessing a comforting or life-sustaining, reality-based belief that a positive future exists for self and others. Interestingly, the inclusion of the phrase "and others" arose from the sample of adolescent cancer patients. He found that only in this sample did adolescent express a concern and articulate their hopes for others. Examples of this attribute included such hopes as "My parent will be O.K if I die," and "There will be a cure soon so patient 'X' will not die". This ability to go beyond oneself and hope for others may be influenced by the adolescents' sense of mortality that accompanies the diagnosis of terminal illness. Despite the stress of life-threatening illness, many adolescents are able to remain hopeful. Ritchie (2010) examined hopefulness and self-esteem in 45 adolescents with cancer. She found that the average hopefulness and self-esteem scores for her sample were as high as those for healthy adolescents. Moreover, high self-esteem was an important predictor of hopefulness. These results suggest that teens are able to respond to serious illness with intact self-esteem and hope.

Although, Esbensen (2008) said chronic illness that impairs physical functioning is linked with decreased hope, diagnosis of a life-threatening disease is not associated with low levels of hope. This finding may reflect on attitude among older adults that the quality of life that remains matters more than the quantity. Among younger European American adults, hope tends to be tied

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to being productive. Personal and professional achievements feature prominently in one’s ability to nurture and maintain hope. In contrast, older adults are more likely to focus on spirituality, relationship, leaving a legacy focused on others, and other factors that are not linked with accomplishment. Hope-fostering activities include reminiscing, participating in purposeful volunteer activities, religious activities, and connecting with others. Summarily hope is central to the human experience of living and dying and it is integrally entwined with spiritual and psychosocial well-being. Although terminal illness can challenge and even temporarily diminish hope, the dying process does not inevitably bring despair. The human spirit, manifesting its creativity and resiliency, can forge new and deeper hopes at the roles in supporting patient and families by providing expert physical and spiritual care. Fostering hope is a primary means by which palliative care givers accompany patients and families on the journey through terminal illness (Ebright & Lyon, 2002).

2.7 Rehabilitative support and palliative care

Rehabilitative service provide complete patient rehabilitation following an illness, injury or surgery with the aim of helping patients and their carers achieve maximum potentials through a multidisciplinary therapy approach. This, essentially, is all about restoration to normal life or near to normal in the event of a terminal illness that have affected the normal functioning of body parts of the sufferer (Oxford Advanced Learner’s Dictionary 2000). Patients are usually referred to the rehabilitative section of the health care facility to benefit from the various activities that are made available for these vulnerable clients. A multidisciplinary team of medical, nursing, social worker, occupational therapy, physiotherapy, speech therapist, pharmacy, pastoral care, dietetics, clinical and neuropsychologist all work together to ensure the best outcomes for all patients. There is a health directorate on aged care and rehabilitative care; these services include prevention assessment, diagnosis, treatment support and rehabilitation for older people (Mueller 2001).

Psychosocial rehabilitation involves interventions which help patients to manage behaviours, perceptions and reactions to the injury or condition which may hold back the process or recovery or maintenance of one’s wellbeing. A rehabilitation programme focuses solely on a package of psychosocial interventions. However, it is more likely that activities will be offered in conjunction with medical and or vocational rehabilitation services. The aim is to change one’s perception of injury, pain, future loss and life changes which can undermine recovery and

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wellbeing. It helps to alleviate anxiety associated with accepting an injury and the recovery process and assist in maintaining or improving wellbeing. Psychosocial interventions help address issues which can undermine and act as barriers to progressing rehabilitation. Psychosocial interventions, recommended by a rehabilitation service provider, may include measures such as: general psychosocial counselling, adjustment/family/relationship counselling, parenting support anger management, basic life skills training, involvement in community support service, self-help or chronic disease/illness support groups, health/fitness and exercise regimes, lifestyle programs, financial counselling, attendant care, home support and accessing accommodation service, (Australian Government Journal on Veteran's Affairs, 2010).

According to Okikiolu (2003), rehabilitation services are provided in as normalized an environment as possible emphasis is on the here and now rather than on problem from the past, work is central to the rehabilitation process. Emphasis is on social rather than medical model, all people have underused capacities that they can develop; all people can be equipped with skills centered on clients' strengths rather than on pathologies. The rehabilitation service department of every health care facility involved in palliative care delivery for the terminally-ill offers in patient and outpatient service which includes physical therapy, occupation therapy and speech therapy (Oshin, 1999). Specialized treatment is provided on a one-on-one basis. Individualized treatments are designed by therapist to address each individual's specific needs and goals. Akinpelu, (2000) explained that physical therapy is designed to restore and maximize functional independence, relieve pain and promote quality of life. Patient and family education is always an important part of every treatment plan. Physical therapy is carried out with the assistance of the physiotherapist, their function is to restore strength and function back to body parts that the illness has affected e.g weakness of the limb. Assisted exercises are done to restore some, if not total function back to the body part affected.

This goes on in sessions and particular attention is paid to the general condition of the patient so as to determine the extent of physical therapy, the health status can cope with. Occupational therapy helps in rehabilitative process as it has or plays dual functions from the recipients of this service. The patients are taught to use their hands in whatever forms of skill they can learn and imitate. Such therapy includes knitting, sewing, shoe making, artistic presentation, weaving baskets and others. Being able to do some of this could both serve as diversional therapy and improve their cognitive ability. Thus, depression could be minimised, if they think less of their sickness (Johnson, 2001). The speech therapist helps patients that suffer

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loss of speech from illness (stroke affecting speech or cancer of the voice box), although might be difficult to restore the full speech but at least some degree of improvement can be achieved. The availability of such facility within a comprehensive health institution offers appreciable degree of comfortability for the terminally-ill. He/she feels being cared for, supported and, thus, the remaining period of her life would be meaningful and not being made to feel relegated. Rogers (1967), founder of client centred therapy, believed that the goal of therapy was to help the patient examine present choice and make decisions about his/her care client-centred therapy or non-directive therapy is a form of treatment in which the client understands his or her present health situation and the choice of management (rehabilitative therapy available) and therapy decides what the goal of treatment would be. Family member's involvement becomes very paramount with that of the health team. This sort of rehabilitative service provides a comfortable and supportive atmosphere for the patient and gives him another lease of life.

In rehabilitative service, controlling reinforcement can be used. This is a technique in which the patient is given a reward for cooperative behaviour towards his recovery strategies. For example, in life limiting illness, patient may have emotional outbursts when he/she does not get his way. This might be in a bid to get attention, if such action is ignored, they will be able to recover from the emotional outburst faster, and can have a reward for acting maturely. Desensitization is another rehabilitative techniques, this is used to help the patient overcome fear and anxiety, by gradually learning to cope with increasingly stressful situations. Thus, anger can be expressed gradually to the person offering rehabilitative service, then to a friend and gradually to the persons that are not nice to the patient. Modeling is a technique in which the patient learns to handle a given situation by observing how someone else would respond to a similar situation. This is usually for the better and turns out to help the patient have some degree of health restoration, and should the inevitable happen, he would exit with a reassuring frame of mind. Group therapy is also helpful in rehabilitation. It involves those patients who are focusing on specific life events, usually conducted in a relaxed atmosphere. Individual participants can share and benefit from the experience of others. (British Medical Journal, 2009).

2.8 Regular visitation and palliative care

The basic need of a terminally-ill is communication as well as being cared for, by significant persons in his existence. A greater percentage of people would like to be informed if they have a terminal illness. When this occurs care may be in the hospital, hospice palliative care centre or the patient's home, whichever of these places, the terminally-ill's regular visitation becomes paramount (Sheldon, 1999). At this sensitive and significant period of the sick person's life, they become aware of attitude displayed towards them by both family members and health team spiritual support is very important during this period. So, the chaplain, religious groups, imam or rabbis play important roles in the life of the dying patient. They pay regular visits to them. Some churches or mosques organise hospital evangelism during which they visit them, play with them, give them gifts like provision, and other food items. This helps improve emotional state (Jcaho, 2011). The visitations provide support to the patients. Long term caring for the terminally-ill can be a chronic stressor that can be associated with anxiety, depression, alteration in the immune system and increased mortality. However, providing support has health benefits as well as instrumental supports to friends, relations and neighbours.

However, emotional support to spouses has been linked to a significant decrease in early mortality. According to Heltz (2000), dying persons have the need to feel valued and accepted, maintain confidence and self-esteem, have their feelings known, be assured of being remembered and also participate in decision-making activities. The hospice becomes very appropriate for the terminally-ill in which the person can die with dignity. The hospice is a facility or program of caring for terminally-ill persons and of counselling their families. This concept is carried out in a home like atmosphere for the terminally-ill. Though this can be arranged in the person's home if the facility for that is available. People can visit such ill patients as they like without restriction. So, the final days of the terminally-ill are made to be as meaningful and pleasant as possible.

2.9 Family integration in palliative care

Recognising the importance of a family necessitates clearly the definition of what is meant by "family." Most often, families in palliative care do consist of patients, their spouses, and their children. But in today's world of divorce and remarriage, step-relatives must also enter into the family portrait. In other instances, people unrelated by blood or marriage may function as family (Panke 2004). Therefore, the definition of family must be expanded. The family is a group of individuals inextricably linked in ways that are constantly interactive and mutually reinforcing. Family can mean direct blood relatives, relationships through an emotional commitment, or the group of persons with which an individual feels most connected (Field & Cassel, 1997). Moreover, family in its fullest sense embraces all generations - past, present,

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future; those living, those dead, and those yet to be born. Shadows of the past and dreams of the future also contribute to the understanding of families.

Palliative care programs are based on the principle that the family is the unit of care. In practice, however, the family is often viewed as a group of individuals who can either prove helpful or resist efforts to deliver care. Nurses and other health care professionals must strive to understand the meaning of the palliative experience to the family (Andershed, 2004). If quality care is to be provided, palliative care provider need to understand how all family members perceive their experience, how the relationships fit together, and that a multitude of factors combine to make families what they are. However, only recently has research gone beyond focusing on the needs of dying patients for comfort and palliation, to addressing issues relevant to other family members. Much of research has focused on the family's perceptions of their needs, (Martin, Berwich & Fyles, 2008), experiences and challenges faced, adaptation and coping skills required for home care, the supportiveness of nursing behaviours or physician behaviours and satisfaction with care. Most research has focused on families of patients with cancer and other terminal illness, (Rhodes, Mitchel & Miller, 2007).

WHO (2000) defined palliative care as an essential component of comprehensive package of care for people with terminal illness, it is an important aspect of care that uses a team approach to address the needs of the patients and their families including bereavement counselling if indicated. The recognition of the family as the unit of care and their support and education are vital. (Tanchel, 2003) affirms that it is important to give time to family members to talk as individuals as well as in a group. There is a close connection between the family, the patient and the disease. In palliative care, the creation of a safe place for families to talk is important. Communication becomes constricted as members try to protect one another from painful feelings, families, thus, need help as the patient either withdraws or wants constant attention. Parkes (2002) highlighted three major issues that can emerge even in well-functioning families which are: acquiring information, concealing feelings and coping with helplessness. Tanchell (2003) reaffirms that neutrality is important and at all times, practitioners should be sensitive and aware of their role within the family. Monroe (1999) warns "if the family finds balance only with his famly rather than helping them find solution", It will create more problem. The diagnosis of terminal illness is traumatic for everyone, hence the knowledge and understanding of the crisis is important as everyone's realities change within seconds. All that was once certain becomes uncertain and the emotional and physical resources of the entire

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family are threatened. Even referral to palliative care service is experienced as a major crisis. Family often means more than blood ties with the patient. It stands, for those relationships that are significant for the patient. A network of attachments existing within a social and cultural context. Thus, friends, neighbours and work colleagues may be equally important and equally affected by the diagnosis of terminal illness.

Findings make it clear that family members look to health professionals to provide quality care to the patient. Family members also expect health professionals to meet their own needs for information, emotional support, and assistance with care (Rhodes & Mitchel 2008). Much of the research that purports to address the impact of terminal illness on the family is based on the perceptions of individuals either the patient or adult family members (usually the spouse). Many of the studies were conducted retrospectively, that is, after the patient's death. But even studies conducted during the palliative period frequently exclude the patients who is the one at the center of the palliative care situation. Examining palliative experience of the family unit has been rare. Davies (1995) identified the basis for offering optimal support to families in palliative care, and the research findings that prospectively examined the experiences of such families. The common view is that transitions are initiated by changes, by the start of something new. However, as Bridges (1998) suggests, most transitions actually begin with endings. This is true for families living with serious illness in a loved one. A transmission that families themselves labeled as "fading away." The transition of fading away for families facing terminal illness began with the ending of life as they knew it. They came to realise that the family member was no longer living with terminal illness, but was now dying from the illness. Despite the fact that family members had been told about the seriousness of the prognosis, and had experienced the usual ups and downs associated with the illness trajectory, for many, the realisation that the patient's death was inevitable, thus becomes evident. A patient once commented:

> *My body has shrunk so much the other day, I tried on my favorite old blue dress and I could see then how much weight I have lost. I feel like a skeleton with skin! I am getting weaker. I just can't eat much now, I don't want to. I can see that I am fading. I am definitely fading away. (palliative care patient 2008:1015)*

The transition of fading away, according to Davies and Steele (2010), is characterised by seven dimensions: redefining, burdening, struggling with paradox, contending with change,

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searching for meaning, living day by day, and preparing for death. The dimensions do not occur in linear fashion; rather, they are interrelated and inextricably linked to one another. Redefining, however, plays a central role. All family members experience these dimensions, although patients, spouses, and children experience each dimension somewhat differently. Varying disease trajectories for other conditions, such as dementia, also influence the nature of support that health carers provide for patients and families. For example, in a comparative study of staff's assessment support needed by families of dementia and cancer patients, staff in dementia care stressed significantly more, the need for forming support groups for families, offering respite care, educating families, and trying to relieve families' feeling of guilt. In the cancer-care group, staff assigned greater importance to being available to listen, creating a sense of security, and supporting the family after death (Albinson & Strang 2003). Furthermore, clinicians are in ideal positions to advocate with politicians and policy makers to expand resources for home-based palliative care programs so that families can adequately and humanely be supported in their caregiving work.

Baker and Teno (2000) explained that supporting patients and other family members with redefining requires that health care providers appreciate how difficult it is for family members to relinquish familiar perceptions of themselves and adopt unfamiliar, unwelcome, and unasked - changes to their self-perceptions. Disengagement from former perceptions and the adoption of new orientations occur over time. Nurses and other care providers are challenged to help family members anticipate and prepare for what lies ahead, while not pushing them at a pace that threatens their sense of integrity. Each family member redefines at his or her own pace; interventions must be tailored according to the individual needs. At the same time, health care providers must support the family as a unit by reassuring family members that their varying coping responses and strategies are to be expected.

Opportunities should be provided for patients to talk about the losses incurred due to the illness, the enforced changes, the adaptations they have made, and their feelings associated with these changes, reinforce their normal patterns of living as long as possible and as appropriate. When they can no longer function as they once did, they can be encouraged to focus on what they can do, reinforcing those aspects of self that remain intact (Vachon, 1998). Acknowledging that roles and responsibilities may be expressed in new and different ways, and suggest new activities appropriate to the patient's interest and current capabilities. The focus with spouses and children centers on explaining how the disease or treatment contributes to changes in the patient

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physically, psychologically, and socially. Temo, Cassey (2009) submitted that spouses should be allowed to talk about how changes in the patient affect their marital relationship, help children appreciate their parent from another perspective, such as in recalling favourite memories or identifying the legacies left, discuss how they can face their own vulnerability by channeling concerns into positive steps for self-care, reinforce the spouse's and children's usual patterns of living for as long as possible and as appropriate when former patterns are no longer feasible, help them to consider adjustments or alternatives (Kissane & Kenzie, 2003), providing opportunities for spouses to discuss how they may reorganise priorities in order to be with and care for the patient to the degree they desire. Considering resources that enable the spouse to do this, the assistance of volunteers, home support services, or additional nursing services is most appropriate as postulated by Bridges (1999).

Caregiving techniques can be taught if the spouse shows interest. With the children, the degree to which they want to be open or private about their parent's illness with those outside the family must be respected. It should also be acknowledged that family members will vary in their ability to assimilate changes in the patient and in their family life. Palliative care team members must realise that not all families communicate openly or work easily together in solving problems. Nurses, in particular, can support patients and family members to contend with change by creating an environment in which families explore and manage their own concerns and feelings according to their particular coping style. Providing information so that families can explore various alternatives helps them to determine what adjustments they can make. They can make information available not only verbally but also in writing. or, tape-record informative discussions so that families can revisit what they have been told (Davies & Seele 2000).

Rituals can be helpful during periods of terminal illness. A family ritual is a behaviour or action that reflects some symbolic meaning for all members of the family and is part of their collective experience. A ritual does not have to be religious in nature. Rituals may already exist, or they can be newly created to assist the family in contending with change. For example, the writing of an "ethical will," whereby one passes on wisdom to others or elaborates on his or her hopes for their loved ones' future, can help ill family members communicate what they might not be able to verbalise to their loved ones (Andershed, 2004).

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2.10 Financial assistance in palliative care

No effective work can be carried out if the terminally ill and their families are worrying about loss of income, identifying financial needs is essential, particularly with families who have to deal with poverty, unemployment and poor housing (Oliviere, 1990). The role of palliative care professional in this area is mainly to assist patient and family on the available health insurance through which the patient can benefit care (e.g NHIS and Premier Medicaid). The social worker has a role to play in this capacity by sourcing for funds through poverty alleviation programmes and possibly grants. Some philanthropist organization could even be consulted for help. This, inadvertently, would give some hope to the patient and family. If financial assistance is available, patient feels less of a burden to others. Terminal illness can result in a number of financial consequences, some of which are related to the inability to perform social roles (e.g unemployment or having to pay for someone else to look after the children/dependent relative). Other bills might become higher as a result of prolonged stay at home, some patients and family care giver may come to find out that their accommodation is not suitable for their altered physical needs, necessitating moving house or adaptation to living environment or moving from upstairs to downstairs. The terminally-ill and their family may need to be involved in planning for the future such as taking steps to make a will and making decisions about who looks after the dependent children.

Those who have a short life expectancy face loss at every level, physical health independence, career, normal family life predictability and future illness. Loss with its antecedent financial involvement represent more than simply a crisis for patients and families, they also present a remarkable opportunity for self awareness, change and growth (Smith 1990).

Practical help can be arranged by the health team attached to the health facility to enable access to financial benefits or legal advice, Liason with local and national statutory agencies, organising package of care at home or negotiating placement and securing funding for residential nursing home care. This social care involves identification and mobilization of resource that will help the patient, family and carers cope with the situation irrespective of whether these are resource within the family or from other voluntary agencies. Fraser (2002) identified the blurring of roles as one feature of multi professional team work. This is more prevalent in psychosocial domain of palliative care. As a result, the team needs to be aware that the risk of overwhelming the patient with psychosocial care may cause difficulties for professionals with the team and if care is not taken, some members may feel undervalued. For financial support to be beneficial, the

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support desired by the provider has to match the support given to him. This is known as matching hypothesis. Psychological stress may increase if a different type of support is provided than what the recipient wishes to receive.

2.11 Physical care and palliative care

The diagnosis of terminal illness, and the severity of patient's condition brings inability for the person to perform normal daily activities of personal hygiene, grooming and other basic self care (Mitchell, 2000). Those with inadequate support are believed to be at much higher risk of death from variety of life-limiting diseases like cancer, cardiovascular diseases and kidney problems. Various studies have shown that increased physical and social support have increased likelihood for longer survival.

Ogunboye (2010) claimed that the important part of promoting physical care is proper grooming. Good grooming consists of practices that keep the body healthy; this helps in psychological satisfaction for the ill patient. Activities of daily living in self care includes taking care of the skin which has to be washed daily, if the patient is weak to do this on his own, the carer can help to do this, using soap, towel and water. The soap would break down oil on the skin and remove dirts that may clog pores on the skin, the skin should be wiped dry with clean towel after bathing, after which talcum powder can be rubbed on pressure points to improve blood circulation to those areas and, thus, prevent breakage of the skin. If the patient is very weak to ambulate, the team involved should turn the patient frequently to relieve pressure on the bony surfaces of the body.

Furthermore, the hair needs attention too. If need be, arrangement can be made for a hair cut with approval from the patient and significant family members involved in his care. If female, the hair can be done neatly and kept tidy, all these activities are part of good grooming. Any dirty clothes should be changed and beddings kept dry to prevent air borne infections and, thus, create psychosocial stability for the patient. Combs and brushes should be appropriately used as required. Cleaning of the mouth is very essential to prevent bad breath and odour coming out from the ill patients mouth, antiseptic mouth wash can be used intermittently for the very ill patient to prevent multiplication of bacteria in the mouth. Finger nails should be kept short and it is better if the family member can assist in some of these simple tasks to give them a feeling of involvement but this should not be enforced. The nature of palliative care is to ensure both psychological and social aspect of care for the terminally-ill in which assistance in every area

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should be rendered for the terminally-ill, hence good grooming and overall physical care helps in health promotion, improves quality of life and ensures dignity. Even when the inevitable happens, the good memory of how their loved ones have been taken care of will help the family cope better in their bereavement (Tanchel, 2003).

In Jeffrey's (2003) view, psychosocial care includes the practical aspects of care such as financial, housing and activities of daily living and overlaps with spiritual care. Spiritual care includes emotional benefits of informal support from relatives, friends, religious groups and pastoral care. Psychosocial care, thus, encompasses psychological approaches, which are concerned with enabling patient and those close to them express thoughts, feelings and concern relating to illness; it also embraces psychological interventions to improve the mental and emotional wellbeing of the patient's families and carers.

2.12 Lifestyle modification and palliative care

This involves a shift from "what used to be" to "what is now." It demands adjustment in how individuals see themselves and each other. Patients maintained their usual patterns for as long as possible, and then begin to implement feasible alternatives once they realized that their capacities were seriously changing. Patients who were unable to redefine themselves in this way attempted to maintain their regular patterns despite the obvious changes in their capacity to do so. They ended up frustrated, angry, and feeling worthless. These reactions distanced them from others, resulting in the patients feeling alone and, sometimes, abandoned (Mehta & Ezer, 2003). For the most part, spouses took the patient's physical changes in stride, they attributed the changes to the disease, not to the patient personally, and as a result, they were able to empathise with the patient. Patients' redefining focused on themselves, the changes in their physical status and intrapersonal aspects; spouses' redefining centered on their relationship with the patient. Spouses did their best to "continue on as normal," primarily for the sake of the patient. In doing so, they considered alternatives and reorganized their priorities (Andershed, 2004).

Sherman (2000) described the "reciprocity of suffering" that family members experience, which results from the physical and emotional distress that is rooted in their anguish of dealing with the impending death of the loved one, and in their attempt to fill new roles as caregivers. The degree to which family members experienced this phenomenon varied according to patients' redefining. When patients were able to redefine themselves, spouses had an easier time. Such patients accepted spouses' offers of support; patients and spouses were able to talk about the

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changes that were occurring, Spouses felt satisfied in the care that they provided. But when patients were less able to redefine, then spouses' offers of support were rejected or unappreciated. In such situations, Jasak (2001) noted that spouses avoided talking about or doing anything that reminded the patient of the changes he or she was experiencing but not acknowledging. The relationship between the spouse and patient suffered. Rather than feeling satisfied with their care, spouses were frustrated and angry, although often they remained silent and simply "endured" the situation. The ill person contributed significantly to the caregiver's ability to cope. Indeed, the ill person was not simply a passive recipient of care but had an impact on the experience of the care giving spouse.

Temo and Cassey (2004) reported that adult children also redefined the ill family member; they redefined their ill parent from someone who was strong and competent to someone who was increasingly frail. Children felt vulnerable in ways they had not previously experienced. Most often, children perceived that the changes in their ill parent were the result of disease and not intentional: "It's not my father doing this consciously." Younger adult children were particularly sensitive to keeping the situation private, claiming they wanted to protect the dignity of the patient, but seemed to want to protect their own sense of propriety. For example, one young woman in her early twenties was "devastated" when her father's urinary bag dragged behind him as he left the living room where she and her friends were visiting. It was difficult for some young adults to accept such manifestations of their parents' illness. Adolescents in particular had a difficult time redefining the situation. They preferred to continue on as if nothing was wrong and to shield themselves against any information that would force them to see the situation realistically (Davies, 2000).

Burdening: Feeling as if they are a burden for their family is common among patients. If patients see themselves as purposeless, dependent, and immobile, they have a greater sense of burdening their loved ones. The more realistically patients redefined themselves as their capacities diminished the more accurate they were in their perceptions of burdening. They acknowledged other family members' efforts, appreciated those efforts, and encouraged family members to rest and take time to care for themselves. Patients who were less able to redefine themselves did not see that they were burdening other family members in any way. They denied or minimized the strain on others (Parke, 2004). The literature provides a comprehensive description of the multidimensional nature of the burden experienced by family caregivers, but no attention has been given to the burdening felt by patients or adult children specifically.

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Caregiver burden, usually by spouses, has been described in terms of physical burden, which includes fatigue and physical exhaustion, sleeplessness, and deterioration of health (Stajduhar & Davies, 1998; Andershed, 2004). Social burden encompasses limited time for self and social stress related to isolation. Regardless of the type of burden, however, most caregivers, including the ones in the leading away studies, expressed much satisfaction with their caregiving (Andershed, 2004). Despite feeling burdened, most caregivers would repeat the experience: "Yes, it was difficult and exhausting, and there were days the patient didn't think he could manage one more minute. But also claims if he had to do it over again, he would not hesitate. He had no regrets for what he has been doing (Brazil & Lohfield, 2009).

Andershed (2004) further commented that children, too, experienced burdening, but the source stemmed from the extra responsibilities involved in helping to care for a dying parent, superimposed on their work responsibilities, career development, and their own families. As a result, adult children of all ages felt a mixture of satisfaction and exhaustion. Their sense of burdening was also influenced by the ill parent's redefining if the ill parent acknowledged their efforts, they were more likely to feel satisfaction (Goy & Carter, 2007). However, children's sense of burdening was also influenced by the state of health of the well parent. If that parent also was ill or debilitated, the burden on children was compounded. If children were able to prioritise their responsibilities they would pay attention to their own needs as well as help their parents, they feel less burdened. Children seemed to perceive caregiving as a task they themselves would do. Of course, they did not have the life experience of a long-term relationship that motivated the spouses to care for their partners, (Davies, 2000). Other palliative care professionals can help patients find ways to relieve their sense of burden, and can provide patients with opportunities to talk about their fears and concerns and to consider with whom they want to share their worries. In this way, patients may alleviate their concern for putting excessive demands on family members. The importance of a break for family members, and suggest that patients accept assistance from a volunteer or home-support services at those times to relieve family members from worry would be quite helpful. When patients affirm family members for their efforts, this contributes to family members feeling appreciated and reduces their sense of burden (Martin & Barwich, 2008)

Nurses and all members of the interdisciplinary team can assist family with burdening by supporting the reassurances to the patient that he or she is not a burden. The family's efforts should be acknowledged when they put their own needs on hold to care for the patient. The

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family caregiver should appreciate the importance of taking care of themselves as a legitimate way of sustaining the energy they need for the terminally-ill. Their positive desires to help must not be neglected. Toscani and Micco (2003) explained the importance of acknowledging the reorganisation action and the considerable adjustment in daily routine of children. They must be encouraged to communicate regularly with their parents by visiting them or phoning them often, the extra effort involved should not be underestimated. Struggling with Paradox stems from the fact that the patient is both living and dying. For patients, the struggle focuses on wanting to believe they will survive and knowing that they will not. On "good days," patients felt optimistic about the outcome; on other days, they succumbed to the inevitability of their approaching demise. Often, patients did not want to "give up" but at the same time were "tired of fighting." They wanted to "continue on" for the sake of their families but also wanted "it to end soon" so their families could "get on with their lives." Patients coped by hoping for miracles, fighting for the sake of their families, and focusing on the good days (Field, 1997; Davies 2000). Children struggled with hanging on and letting go to a greater extent than their parents. They wanted to spend time with their ill parent and also to "get on with their own lives." Feeling the pressure of dual loyalties (to their parents and to their own young families), the demands of both compounded the struggle that children faced (Field & Cassel 1997).

2.13 Re-allocation of roles and palliative care

Those facing terminal illness in a family member experience changes in every realm of daily life-relationships, roles, socialization, and work patterns. The focus of the changes differed among family members. Patients faced changes in their relationships with everyone they knew. They realised that the greatest change of their life was underway, and that life as they knew it would soon be gone. They tended to break down tasks into manageable pieces, and increasingly, they focused inward. The greatest change that spouses faced was in their relationship with the patient (Davies, 2000). They coped by attempting to keep everything as normal as possible. Children contended with changes that were more all-encompassing. They could not withdraw as their ill parent did, nor could they prioritise their lives to the degree that their well parent could. They easily become exhausted. Mehta (2003) analysed the focus thus: Searching for meaning which has to do with seeking answers to help in understanding the situation. Patients tended to journey inward, reflect on spiritual aspects, deepen their most important connections, and become closer to nature: "The spiritual thing has always been at the back of one's mind, but it's

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developing more. When one is sick his/her attitude changes towards life. You come not to be afraid of death. Perreault and Fothergill (2004) claims that spouses concentrated on their relationship with the patient. Some searched for meaning through personal growth, whereas others searched for meaning by simply tolerating the situation. Some focused on spiritual growth, and others adhered rigidly to their religion with little, if any, sense of inner growth or insight. Once pain was controlled, they felt peaceful and relaxed and interpreted this as an indication that the couple would return to their old routines. The patient's meaning of the experience, however, often focused on future consequences of the pain. The meaning attributed to the patient's experience also influenced spousal bereavement. (Martin, Barwich & Fyles, 2008). For example, spouses who witnessed the patient die a painful death, and who believed that physician's negligence was the cause of the pain, experienced elevated anger and much distress after the death (Carr ,2003).

Traditionally, palliative care practice and discussions have focused on families of cancer patients. At the same time, care of the patient with cardiac disease, for example, has traditionally focused on restoring health and enabling a return to normal life. So, the idea of providing a patient with aggressive versus palliative treatment has, until recently, not been a well- discussed issue in the treatment of the patient with heart disease. For most patients with heart disease, and particularly for those with heart failure, the decline in functional status is slower than for patients diagnosed with cancer. Barnes (2006) reported that if palliative care is considered only after disease-related care fails or becomes too burdensome, the opportunity for patients to achieve symptom relief, and for patients and family members to engage in the process of fading away, may be lost. Consequently, following a model of care wherein issues of treatment and end-of-life care are discussed early and throughout the illness trajectory facilitates patient and family coping, and enables nurses to optimally support families.

2.14 Centre for palliative care Nigeria

Palliative care was formally introduced to the Nigerian government policy maker and general public in 2003 through the palliative care initiative Nigeria (PCIN) known as Centre for Palliative Care Nigeria (CPCN), based at the College of Medicine, University of Ibadan. PCIN is a multidisciplinary group of medical specialists who implement the major objective of training, service and research in these areas. Their aim is to sensitise the public on the importance of palliative care. The centre operates a pain and palliative care clinic at the University College

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Hospital, Ibadan. This was commissioned in 2005 to provide support for patient with chronic pain and those with pain, from terminal disease condition (Soyannwo, 2005). In its current form, as a chapter of the International Association for the study of pain, the group is working towards including palliative care into the curriculum of medical and nursing students, based upon the guidelines developed by Hospice Africa, Uganda. Funding has been obtained to develop home based palliative care service. A training the trainers programme is expected to produce locally trained palliative care practitioners.

Soyannmo (2004) envisaged palliative care as a helpful approach in the management of HIV/AIDS epidemic in Nigeria; she added that the template upon which palliative care and pain management was successfully implemented among women with terminal disease for breast and cervical cancers could also be used to manage the pain associated with HIV/AIDS and other life limiting diseases.

Centre for palliative care Nigeria (CPCN) is a not-for-profit organization which was set up to champion the cause of palliative care in Nigeria. Palliative care involves treatment of pain and distressing symptom associated with life limiting illness and providing support (psychological, social and spiritual) for patient. Such all encompassing (holistic) type of care is hitherto not available in Nigeria despite millions of patients and families that can benefit from such care.

Since 1996, members of CPCN have been at the forefront in a bid to making strong pain medication (opioids, including oral morphine) available in Nigeria, and also to developing pain management and palliative care education and services in the country. Through special training courses and workshops, over 200 health professionals (doctors, nurses, social workers, pharmacists, and physiotherapists) have been trained by the organisation. Its collaboration with the University College Hospital, Ibadan has led to the establishment of the first palliative care service in Nigeria which include providing care for in-patients, running a special outpatient clinic, day care hospice and home-based care for those patients and families with challenging end of life issues, especially unrelieved pain. In spite of these achievements, the organisation needs to forge ahead and maintain its leadership and pioneering role. The aim of CPCN is to promote the best possible quality of life for people (and their family members) living with life-limiting diseases/terminal illnesses in Nigeria, including cancer, HIV/AIDS, neurological disorders, end stage kidney diseases, and complicated heart diseases.

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The home-based palliative care programme of the organisation was commenced with a 'start-off' grant from Hospice Africa UK. This program will require further funding to be well established and increase coverage. Other proposed projects of CPCN, for which funding is being sought, include: subsidy for drugs, dressings and transportation, food and hospital bills. The organisational development of CPCN include:

Conducting training for doctors, nurses, social workers and pharmacist from various health facilities in Nigeria to develop a core group of palliative care specialists for the nation, training of allied health workers, care givers and volunteers on the concept of holistic care, training of team members and also assisting and monitoring other organisation in Nigeria to establish palliative care training and service. The University of Nigeria Teaching Hospital, Enugu and Federal Medical Centre, Abeokuta also have Palliative Care Units.

2.15 Empirical studies

Some relevant empirical studies referred to as the record of direct observations and experiences of previous work on palliative care are hereby highlighted.

The volume of research in palliative care has grown dramatically in the last decade. George (2002) found one thousand articles on end-of-life issues of which four hundred were empirical studies. However, there remains important areas that are yet to be adequately addressed (Penrod, Morrison 2004). Under researched arrears include barriers to assessing palliative care, supportive services, psychosocial and spiritual issues. World Health Organization (2004) highlighted the importance of palliative care of older people and those from different cultures.

Onyeka's (2013) work on *21st century palliative care: A tale of four* nations provides a focused review on the progress of palliative care practice in four developing nations (i.e Nigeria, Georgia, Ethiopia and Tanzania) Onyeka and colleagues highlighted the specific challenges unique to each nation and proposed steps needed for the growth of palliative care services in these four nations. This work served as a stimulus for increasing global awareness of palliative care in the developing world and for promoting the establishment of palliative care in developing countries where such services are still lacking.

Clinical components of palliative care in Nigerian hospitals by Soyannwo and Kuye (2007) revealed that palliative care is broader than end of life care or terminal care. It complements therapies that aim to cure or control underlying disease. The major problems that

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constitute these components include pain, weakness, fatigue, intestinal and urinary problems with skin problems. The outcome, thus, revealed that palliative care should aim at achieving best quality of life for both patients and family, relationship network should be made to feel informed and supported even if the inevitable happens and lastly the health care group that accepts the goals of care, ask the expertise and compassion to deliver quality care for the palliative patients.

Furthermore, Elumelu, Adenipekun, Soyannwo, Aikomo, Amanor-Boadu and Ogundelu researched on palliative care experience in breast and uterine cervical cancer patients in Ibadan, Nigeria. The study was carried out by reviewing the case notes of all patients with advanced cervical and breast cancer that received palliative care in the newly established hospice and palliative care unit of UCH within a period of thirty months (2008-2010). Palliative measures applied include medications, assessment of response to care, assessment of level of satisfaction to care provided. Out of 178 patients, reviewed 80 had cervical cancers, while 98 had breast cancers.

About ninety three percent of these patients presented with pain, most commonly used drug was oral morphine. Approximately fifty eight of these patients were not resident in Ibadan, financial constraint was the most reported psychosocial issue 24.1percent, 36.5 percent have gone back to where they were referred from. 57.3percent were reported dead while 6.2percent were still receiving care from the palliative care team. The study concluded that pain was a major symptom at presentation for majority of the patients used for the study. The percentage of the patients resident outside Ibadan was high in comparison with those resident in Ibadan. Indicating additional travel cost to receive treatment.

Literature has identified that palliative care of the terminally-ill and those with life limiting illness, though on expanding field, funding is limited and has been largely contingent on the pharmaceutical industry in pursuit of approval for analgesics and other agents to address symptoms concerned (Ferrel, 2004). Worryingly, there is lack of funding by foundations and government agencies. Only a small share of cancer research funding is devoted to palliative care in the United States, though each death potentially affects the well-being of an average of five other people (Standing Committee on Social Affairs, 2000).

Research on exploring the transition from curative care to palliative care conducted by Gardinar, Ingletion, Gott and Ryan (2011) revealed that little is known about the potentially complex transition to palliative care, evidence thus suggested that continuity of care and multidisciplinary collaboration are crucial in order to improve the experience of patients making

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the transition. An important role is outlined for generalist providers of palliative care. Incorporating palliative care earlier in the disease trajectory and implementing a phased transition appear key components of optimum care.

Another study on the role of dignity in end of life care as reported by Chochinov (2012) who examined how patients nearing death understand the notion of dignity and what factors undermine or maintain dignity at the end of life.

The result of this study was an empirical model of dignity which has informed various aspects of research programme. The model of dignity in the terminally ill forms the basis of a novel intervention called dignity therapy. This individualised, brief psychotherapy has been designed specifically to maintain the dignity of dying patients and their families. This study also informs the understanding of how notions of personhood are important to acknowledge in pursuit of dignity conserving care.

Morgan, Massaro and McMillan (2000) examined the assessment of quality of life at the end of life in palliative care, it was emphasised that selection of the appropriate quality of life instrument depends on the purpose of the assessment and characteristics of the patients, they reported that the instrument must measure all aspects of quality of life that may be affected by a life limiting illness. It was concluded that there was little evidence to suggest the impact of specialist palliative care on patients' quality of life.

Godwin (2003) measured the effectiveness of palliative day care in improving pain, symptom control and quality of life, he made use of prospective comprehensive study, Mcgill quality of life (MQOL) and Palliative care Outcome Scale (POS), Result was that the day care group has better pain control at the first assessment and symptom control at the second interview than the comparison group within the day care group. The palliative care outcome scale item 'symptom control was significantly worse by the final interview. Both groups maintained overall quality of life during the three months of the study.

The hospital quality of life index (HQLI) administered within 48 hours of admission and three weeks after hospice care evaluated the outcomes of hospice services and explore factors that affect quality of life. The result found that quality of life of hospice patients was reasonably good and stable over the course of three weeks of care. The individuals were most satisfied with social/spiritual aspects of quality of life and were least satisfied with physical functional aspects of quality of life. Highest scores related to the support patients perceived from family and friends, the physician and the hospice team (Mcmillan & Mahon, 1994).

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Despite most literature emphasising various available palliative care programs, Jarvis, Burge and Scot (1996) on evaluating palliative care outcome surveyed physicians nurses family members and patients' assessment. Result revealed symptom relief satisfaction with care for patients/families, good nursing morale and reduced stress for other staff members. The two components of programme rated most highly were the availability of care and the psychosocial support given to families and patient's satisfaction with information regarding side effects of treatment was also reported. Availability of care givers and adequate information about tests performed was greatest in the palliative care unit as compared to home care.

Lee (2006) in her study examined controlling involvement to promote confidence in palliative care decision-making (made use of grounded theory), she explored the perspective of patients with advanced illness, their experiences and making care decisions. The findings indicate that partnerships between conditions for decision-making in palliative care provide the most favourable conditions for decision-making in palliative care where patients can comfortably communicate their decision needs. However, her findings contradict models of patient participation which favour patients being independent decision makers, though the content and process of communication with patients and the importance of identifying the needs of family members as separate to the needs of patients in care decision-making.

Herth (2000 & 2001) tested a Hope Intervention Programme (HIP) which she evaluated in the sample of people with recurrent conditions of life limiting illness (cancer). Based on her empirically derived theory of hope, the intervention consisted of eight sessions delivered in a nurse facilitated group setting; six sessions focused on strategies that specifically address the four hope processes: experiential, relational, spiritual and rational thought. During the final session, participants developed an individual plan with strategies to maintain and foster hope, when Herth tested this intervention, she found significantly increased hope levels in the treatment group compared with two control groups. This significant difference persisted at three, six and nine month follow-up measurement.

Cantrell and Conte (2008) adapted the hope intervention programme for internet use and conducted a pilot test with six female survivors of childhood cancer. This innovative delivery method showed promise as a strategy to bridge geographic distances and may appeal to individuals who are more comfortable communicating online.

Hinds, Quargnenti and Fairclough (1999) developed a psychosocial Research Translation Team to integrate evidence - based hope intervention guidelines into a terminal care department

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at St. Jude Hospital, in United Kingdom. Using this innovative approach, the multidisciplinary team reviewed the literature in hope and interviewed experts on the topic. The team used this information to develop its own definition of hope and to identify potential projects aimed at translating the evidence - based guidelines on hope into practice, the projects included adding information about hope to patient's handbook, developing patient/family and staff educational sheets about hope, developing a telephone hotline that allows for effective delivery of messages and designing and launching websites about hope. This program demonstrated the creative and diverse approaches that palliative health care providers can use to support and promote hope among patients and families facing life threatening illnesses.

One of the goals of palliative care is to provide psychosocial support to patient and families facing terminal illness. Psychosocial care has been defined as concerned with the psychological and emotional well-being of the patient and their family/carers including issues of self esteem, insight into an adaption to illness and its consequences, communication social functioning and relationship (Macleod, 2008). The earliest systematic reviews of interventions for family carers of palliative care patients were conducted by Harding and Higginson (2003). Key data basis were searched for reported intervention. Their review identified twenty-two cases related to interventions, five interventions were evaluated via randomised controlled trials. A range of intervention approaches was identified including home care, respite care, social networks and activities, problem solving and education, one on one therapy and group work. They concluded that there was only a small body of evidence regarding the effectiveness of interventions for carers of cancer and palliative care patients; the bulk of the evidence came from a small number of studies that were graded as moderate to weak in terms of rigour. Furthermore, evaluating the status of supportive interventions for carers was acknowledged as one of the priorities for the international palliative care family care research.

Two other studies conducted by Duggleby (2007) via qualitative data method reported that carers perceived psychosocial support intervention as beneficial. They conducted a pre-test/post-test study intended to promote hope among carer while the study sample size precluded statistical analysis, the qualitative responses indicated that the programme was received favourably. Milberg (2005) found that regular support group sessions for family carers of palliative care patients were also perceived as beneficial when follow up evaluations were conducted. All participants reported that they would recommend a support group to others in a similar situation.

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Canadian Cancer Society (2007) investigated on the availability of rural models for the delivery of palliative care services. \Several reports were identified which outline rural palliative care delivery models. Many of these explicate a model of partnership between urban and rural providers, or the development of palliative care networks and linkages between rural hospitals and home care services. Others have concluded that the difficulty in accessing specialist palliative care services and support within the rural community indicates that such a model of specialist palliative care or hospice as a site of care may be more suitable as an urban model (Evans, Store & Elewyn, 2003). This conclusion was reached mainly because of the models in rural areas. It was then deemed better to think of hospice palliative care as a philosophy of care rather than as a site of care. Further evidence must, thus, be focused on furthering understanding of how best to meet the palliative care needs of rural dwellers, their caregivers and the professionals who serve the rural community.

Qualitative study carried out by Conley and Barman (1997) on the informational needs of primary care giver of terminal patients who receive home care while in a rural setting. The subjects were interviewed over a period of twelve months of the family members' death. Average percentage of respondents recorded overall satisfaction with information available during care provision stress and exhaustion were reported. The identified specific needs were information about patient's disease progression, symptoms, side effects and treatment options with expectation. Available supports through health care and other agencies. Hospice and home care specialist need to function effectively to assist caregivers, focus more on addressing caregiver stress and coping. Finally, community resources must be continually reassessed and work should be geared towards filling the gaps.

Passik (2002), in his pilot study of oncology staff perceptions of palliative care in rural and community settings, explored perceptions on difficulty in managing symptoms and side effects associated with managing cancer symptoms and availability of hospice care and barrier to obtaining services. Results show less than optimal delivery of palliative care in rural settings, confusion of services hinders continuity as regards availability and integration of palliative care into clinics. The major problem seen with pain control and other physical symptoms are a mandatory first step in palliative care. Poor integration of multidisciplinary care resulted in inadequate management.

White and Jaes (2005) examined the impact of being part of the palliative care family on the families of terminally- ill, seventeen families were used for the study. Their finding emerged

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thus: One or more members in a family took prime responsibility for care; some claimed the burden was exhausting. Family carers were generally untrained but willing (though they feared doing the wrong thing); not knowing what to expect made the experience more difficult; food for the ill person was an essential component of caring; physical care becomes an issue as the patient's condition worsened. The family carer relied on the nurse to provide equipment and teach them how to use it as well as giving medications. Finally, the community, the neighbours and family support became more evident, especially if that family had been a long term resident in the area.

Oyebola (2007) looked at the role of palliative care in the era of Antiretroviral therapy (ART) and vice-versa, solely on clients with HIV/AIDS, he discovered the need to address the ethical issues surrounding the disease epidemic, stressed the need for equal distribution of appropriate drugs and that palliative care must be accessible and affordable, as such should be a fundamental right of every HIV positive client.

Akeredolu (2008), however, reviewed gender issues in palliative care. She, as the founder and President, Breast Cancer Association of Nigeria (BRECAN), highlighted the existence of gender issue for women with terminal illness. The cultural and community expectation of the roles women play as the family carer, concerns that women do not come out to the open early enough, thereby fail to receive adequate income and concern about who to take care of children as a result of disease progression. The essence of appropriate health education was thereby highlighted to assist them out of ignorance.

2.16 Theoretical framework

The relevant theoretical framework for this study is; the sociological theories of illness and health care, which are structural functionalism theory and symbolic interactionism theory.

Structural functionalism theory

- Structural functionalism began with Herbert Spencer (an English Sociologist) known for coining the phrase "survival of the fittest" in his book titled "Principles of Sociology" 1986. In 19th century, Emile Durkhelm laid the primary foundations for structural functionalism.

  This structural functionalism has a theoretical understanding of society that conceives social systems as collective means to fill social needs. In order for social life to survive and develop, there are a number of activities that need to be carried out to ensure that

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certain needs are fulfilled. In the structural functionalist model, individuals produce necessary goods and services in various institutions and roles that correlate with the norms of the society (Gingrich, 1999).

The use of structural functionalism as a framework for this endeavour is predicated upon the premise that palliative care (as a dependent variable) can be categorized as a social institution: a collection and integration of care designed to address the needs of the primary stakeholder i.e. the terminally-ill patient. In addressing the needs of the terminally-ill patient, this study will attempt to determine the efficacy of other 'collective means'/social institutions (psychosocial support and family integration) as determinants of a *social subsystem* (palliative care) in terminally-ill patients at the University College Hospital, Ibadan, Nigeria. At a micro level, the structural functionalism slant of this study is founded upon the orientation that psychosocial support and family integration are critical to the quality, scope and depth of the palliative care provided to terminally-ill patients at the University College Hospital (UCH) Ibadan, Nigeria

There are a number of key assumptions in Structural Functionalism theory. One of the assumption is that institutions are distinct and should be studied individually. Many Structural Functionalists look at institutions individually as though they are divorced from other institutions. This is a mistake, as institutions are interlinked in society and those employing a structural functionalist approach should take into consideration the network of relationships that exist between these institutions. (Davis & Moore, 1984). The palliative care of terminally ill patients cannot be looked at in isolation given their interconnectedness to psychosocial support and family integration.

Structural Functionalism views society as constantly striving to be at a state of equilibrium, which suggests there is an inherent drive within human societies to *cohere* or stick together. This is known as the cohesion issue (Hark & Durk, 2007). Societies strive towards equilibrium, not through dictatorial mandate by the leaders of society but rather because the social structure of societies encourages equilibrium. This study will look into the traditional and practical cohesiveness of psychosocial supports and family integration endemic in palliative care. Palliative caregivers stick together as individuals and parts of a group with a unifying objective of catering for the terminally-ill. Psychosocial supports and the family (as an integral unit) as social subsystems coalesce in the palliative care of terminally-ill patients.

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This is in line with how classical functionalist theories are defined: by a tendency towards biological analogy and social evolution. As an advocate of the classical functionalist; Giddens, (1984) stated: Functionalist thought, from Comte onwards, has looked particularly towards biology as the science providing the closest and most compatible model for social science. Biology has been taken to provide a guide to conceptualising the structure and the function of social systems and to analysing processes of evolution via mechanisms of adaptation functionalism strongly emphasises the pre-eminence of the social world over its individual parts (i.e. its constituent actors, human subjects).

Structural Functionalism also has an anthropological basis in the work of theorists such as Radcliffe-Brown (2004). It is in Brown's specific usage that the prefix 'structural' emerged. Radcliffe-Brown believed that society constitutes a separate "level" of reality, distinct from both biological and inorganic matter. Individuals are, therefore, merely transcient occupants of comparatively stable social roles. The predictability of psychosocial support and family integration in palliative care of the terminally-ill is an example of stable social roles given the need for humanity to live in harmonious adjustment to one another.

Herbert Spencer, a British philosopher famous for applying the theory of natural selection to society was in many ways the first true sociological functionalist (Cuff & Payne, 1998). While Durkheim is widely considered the most important functionalist among positivist theorists, it is well-known that much of his analysis was culled from reading Spencer's work, especially his *Principles of Sociology* Spencer compares society to the human body. Just as the structural parts of the human body - the skeleton, muscles, and various internal organs - function independently to help the entire organism survive, social structures work together to preserve society (Cuff & Payne, 1998).

Spencer concluded that society is constantly facing selection pressures (internal and external) that force it to adapt its internal structure through differentiation. Every solution, however, causes a new set of selection pressures that threaten society's viability. It should be noted that Spencer was not a determinist in the sense that he never said that selection pressures will be felt in time to change them, they will be felt and reacted to; or the solutions will always work. Spencer recognised that the degree of centralised and consolidated authority in a society could make or break its ability to adapt. In other words, he saw a general trend towards the centralisation of power as leading to stagnation and ultimately pressures to decentralise. More specifically, Spencer recognised three functional needs or prerequisites that produce selection

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pressures: they are regulatory, operative (production) and distributive. He argued that all societies need to solve problems of control and coordination, production of goods, services and ideas, and, finally, to find ways of distributing these resources. The regulatory environment within which palliative care (as a subset of society) function must be such that the well-being of the terminally-ill must be of paramount importance at all times. In this context, psychosocial support and family integration provide the yardstick within which the quality, depth and scope of palliative care are measured.

Durkheim proposed that most stateless, "primitive" societies, lacking strong centralised institutions, are based on an association of corporate-descent groups (Nolan & Lenski, 2004). Durkheim was concerned with the question of how certain societies maintain internal stability and survive over time. He proposed that such societies tend to be segmented, with equivalent parts held together by shared values and common symbols. Durkheim used the term "mechanical solidarity" to refer to these types of "social bonds based on common sentiments & shared moral values, which are strong among members of pre-industrial societies (Parson & Shills, 1999). In modern, complicated societies, members perform very different tasks, resulting in a strong interdependence. Durkheim argued that complicated societies are held together by organic solidarity. The central concern of structural functionalism is a continuation of the Durkheimian task of explaining the apparent stability and internal cohesion needed by societies to endure over time. Societies are seen as coherent, bounded and fundamentally relational constructs that function like organisms, with their various parts (or social institutions) working together in an unconscious, quasi-automatic fashion toward achieving an overall social equilibrium. All social and cultural phenomena are therefore seen as functional in the sense of working together, and are effectively deemed to have "lives" of their own. They are primarily analysed in terms of this function. The individual is significant not in and of himself, but rather in terms of his status, his position in patterns of social relations, and the behaviours associated with his status. Therefore, the social structure is a network of statuses connected by associated roles.

Talcott Parsons was influenced by Durkheim . For Parsons, "the social system is made up of the actions of individuals **(**de Maio, 2010). His starting point is the interaction between two individuals faced with a variety of choices about how they might act (Tumin, 2001). These choices are influenced and constrained by a number of physical and social factors (Kuper, 1988)

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Parsons determined that each individual has expectations of the other's action and reaction to his own behaviour, and that these expectations would (if successful) be "derived" from the accepted norms and values of the society they inhabit (Tumin, 2001) According to him, in a general context there is no perfect "fit" between behaviours and norms, so such a relation is never complete or "perfect." Parsons never claimed that social norms were generally accepted and agreed upon. This to him, was simply a historical question. The cohesion and interdependency of the subsets that compromise the effectiveness of palliative care cannot be taken lightly. Psychosocial support and family integration must individually and collectively constitute a seamless piece of the puzzle. The whole is more than the sum of its individual parts.

Symbolic Interactionism Theory

The term ‘‘symbolic interactionism’’ was invented by Blumer (1999) to describe sociological and social psychological ideas he presented as emanating directly from Mead, ‘‘Symbolic interaction theory’’ is a term that is related to those ideas, though not necessarily in the specific forms presented by Blumer or Mead.

Its theoretical proposition considers the self to reflect society and organises behaviour that addresses the nature of human interaction, and the relationship between society and the person. Its imagery begins with a vision of society as a web of communication: Society is interaction, the reciprocal influence of persons who, as they relate, take into account each other’s characteristics and actions, and interaction is communication. Interaction is ‘‘symbolic,’’ meaning it is conducted in terms of the meanings people develop in the course of their interdependent conduct. The environment of human action and interaction is symbolically defined: It is the environment as it is interpreted that is the context, shaper, and object of action and interaction. Persons act with reference to one another in terms of symbols developed through interaction and act through the communication of those symbols. Society is a label aggregating and summarising such interaction. Society does not ‘‘exist’’; it is created and continuously re-created as persons interact. Social reality is a flow of events joining two or more persons. Palliative care is not a one-size-fit-all proposition. In the same vein, the psychosocial support and the integration of the family of the terminally-ill patient as a cohesive unit are not a cookie cutter proposition. At the nucleus and center of this independent variable is the individual, profile and personal characteristics of the terminally-ill patient. More than simply being implicated in the social process, society and the person derive from that process: They take on their meanings as those meanings emerge in and through social interaction.

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Neither society nor the individual is ontologically prior to the other in this imagery; persons create society through their interaction, a web of communication and interaction that creates persons as social beings. Society and the individual presuppose each other. This conception of society incorporates a view of the human being as ‘‘minded’’ and that ‘‘mindedness’’ as potentially reflexive. That is, people can and sometimes do take themselves as the object of their own reflection, thus creating selves, and doing this from the standpoint of the others with whom they interact. Selves are inherently social products, although they involve more than reflected appraisals of others in the immediate situation of interaction; selves involve persons as subjects responding to themselves as objects. Thinking takes place as an internal conversation that uses symbols that develop in the social process. Mind arises in both the evolutionary and individual senses in response to problems (interruptions in the flow of activities) and involves formulating and selecting from symbolically defined alternative courses of action to resolve those problems. Choice is an omnipresent reality in the human condition, and the content of choices is contained in the subjective experience of persons as that experience develops in and through the social process.

Following this imagery is a view of human beings, both collectively and individually, as active and creative rather than simply responsive to environmental stimuli. Since the environment of human action and interaction is symbolic; because the symbols attached to persons (including oneself), things, and ideas are the products of interaction and reflexivity and can be altered and manipulated in the course of that interaction; since thought can be used to anticipate the effectiveness of alternative courses of action in resolving problems; and because choice among alternatives is an integral feature of social conduct, one arrives at an image of social interaction as literally constructed, although not necessarily anew in each instance and in the course of interaction. This could result in an indeterminate human behaviour in the sense that the course and outcome of social interaction cannot, as a matter of principle, be completely predicted from conditions and factors existing before that interaction. Palliative care services do not exist in a vacuum. What makes them possible and valuable are their interaction and congeniality relative to the terminally-ill patient. Conversely, psychosocial support and family integration are stand alones as individual social subsystems within unique and distinctive characteristics. However, what gives them value and distinctiveness is the synergy and flavour palliative care provide.

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The **s**elf refers to the conscious, reflective personality of an individual. It is the entity the person envisions when he/she thinks about who they are. In order to understand the concept of self, it is important to understand that the development of self is only possible through role-taking. In order to look upon one*self*, the individual had to be able to take the role of another, which, in turn, allows you to reflect upon your *self*. Because role-taking is a necessary part of self-development, it is concurrent with the development of self. Empathy is a critical ingredient in palliative care. Psychosocial supports and family integration are effective in palliative care depending on the depth of the empathy demonstrated by the various actors involved. At the most rudimentary level, empathy is not about listening to another in order to generate a response but to understand. Understanding does not come from the head but the heart.

According to Mead (1967), the self develops in a series of three stages:

1. preparatory stage - meaningless imitation by the infant.
2. play stage - actual playing of roles occurs, but no unified conception of self develops.
3. game stage - this is the completion stage of self-development; the child finds who he or she is; the child also must respond to simultaneous roles; the individual can act with a certain amount of consistency in a variety of situations because he/she acts in accordance with a generalized set of expectations and definitions he/she has internalized.

The *self* consists of two parts, the *I* and the *Me*. The *I* is the impulsive tendency of the individual and the spontaneous, unorganized aspect of human existence. The *Me* is the incorporated other within the individual. The incorporated or generalized other supplies an organised set of attitudes and definitions, understandings and expectations) that are common to the group to which the individual belongs

According to Mead (2004) presentation of the 'I' and the 'M*e'* action begins in the form of the *I* and ends in the form of the 'Me' the 'I' gives propulsion while the Me gives direction. Additionally, the ***I,*** being creative and spontaneous, provides for change in society. The M*e*, being regulatory, works to maintain society. Thus, the concept of *self* is a powerful and comprehensive understanding of how humans function in society and, in turn, how society functions (by both changing and remaining constant). The concept also depicts the relationship between the individual and society (Meltzer, 1999).

According to Meltzer (1999), there are three implications of selfhood: the possession of self makes the individual a society in miniature; humans can engage themselves in interaction they can view themselves in a new way, the ability to act toward oneself makes possible an inner

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experience which needs not reach overt expression; humans can have a mental life and an individual with a self can direct and control his behaviour. It is also important to recognize that the self and the mind are twin emergent in the social process.. The *Mind* or mental component of man emerges out of human communication. The mind is only present when significant symbols (as opposed to gestures that do not have meaning but simply evoke responses) are being used in communication. In this sense, *mind* is a process manifested whenever the individual is interacting with himself using significant symbols (symbols or gestures with interpretations or meanings). The mind is also the component of the individual that interrupts responses to stimuli. It is the mind that attempts to pre-vision the future by exploring possible outcomes of actions before proceeding with actions. In minded behaviour, the individual carries on an internal conversation.

The basic assumptions of symbolic interactionism, according to Herman and Reynolds (1994), are: humans live in a symbolic world of learned meanings, symbols arise in the social process and are shared, symbols have motivational significance; meaning and symbols allow individuals to carry out distinctively human action and interaction. The mind is a functional, volitional, teleological entity serving the interests of the individual; humans, unlike the lower animals, are endowed with the capacity for thought; the capacity for thought is shaped by social interaction, the self is a social construct; just as individuals are born mindless, so too, are they born selfless. Our selves arise in social interaction with others, society is a linguistic or symbolic construct arising out of the social process; it consists of individuals interacting and sympathetic introspection is a mandatory mode of inquiry.

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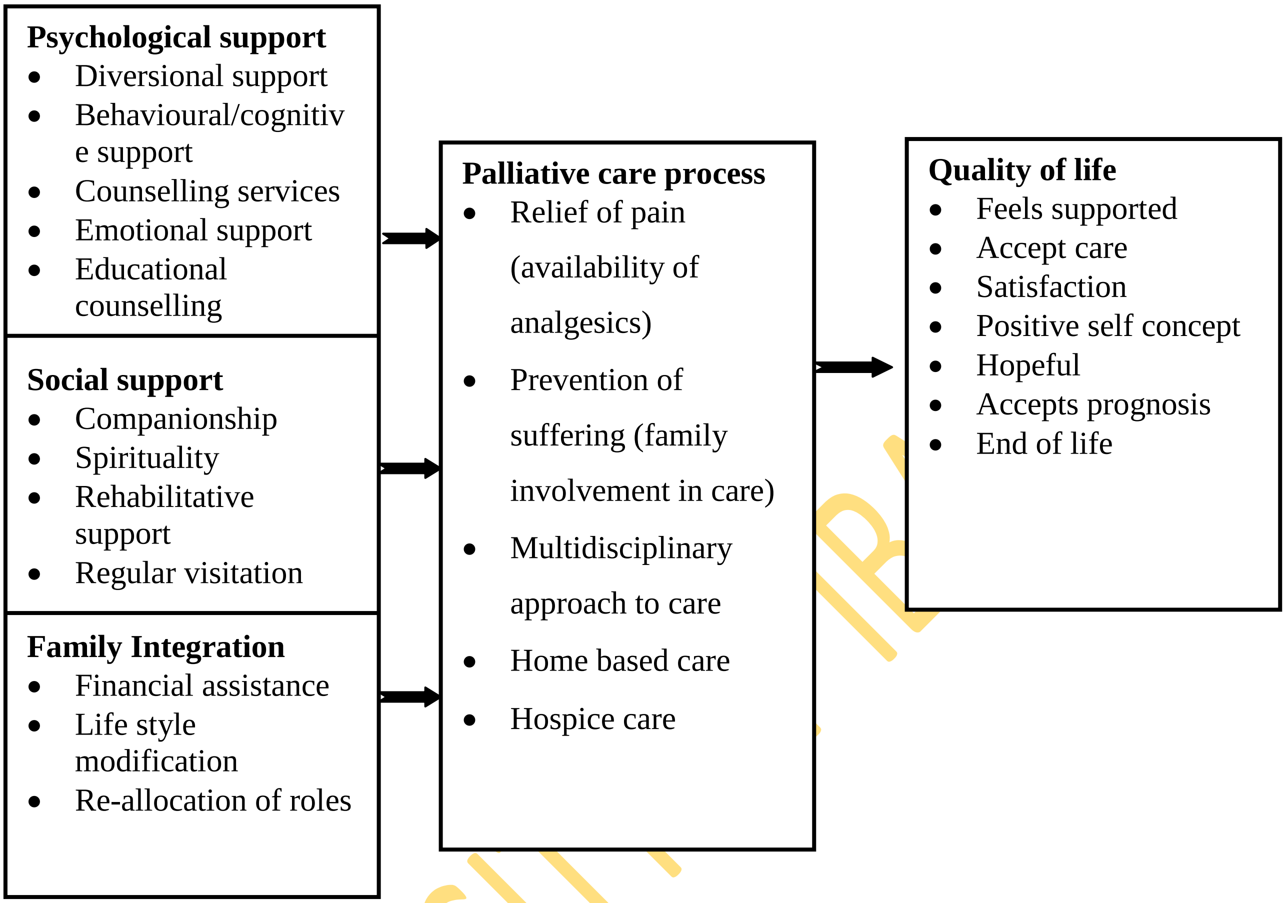
Framework for psychosocial supports and family integration in relation to palliative care process and quality of life of terminally ill patients



Adapted from Macmillan & Mahon (2004)

In this framework, structural functionalism is a function of different part of the system working cohesively together to produce a state of equilibrium. The above framework explains the three different independent variables with the component of each as they significantly lead to palliative care process in order to ensure good quality of life. Given the fact that society needs to solve problems and coordinate the regulatory environment within which palliative care process functions, this must be such that the well-being of the terminally-ill is regarded as most important.

Symbolic interaction theory is a powerful and comprehensive understanding of how an individual functions in society, thus ‘self’ takes a pivotal role in that all domains of psychological and social support with family integration are relative variables in palliative care process. This is an example of stable social roles given the need for humanity to live in harmonious adjustment to one another. This would help to improve the quality of life of the individual i.e. “self”, which represents the society that takes on their meaning through social interaction with one another. (social support).

2.17 Appraisal of Literature

The literature has reviewed the following

2.17.1 Research Issue: The burden of terminal illness is increasing worldwide due to the rise in the prevalence of cancer, heart disease, neurological problems and HIV/AIDS with increasing proportion of the elderly among us. In addition, there is increasing urbanization, industrialization, and westernization of dietary and other socio behavioural attitudes in most developing countries. In Africa alone, it is estimated that about 2.5 million people die annually from HIV/AIDS, while more than 0.5 million die from cancer and other debilitating diseases. As a result of this, one is overwhelmed by the large number of patients needing palliative care.

This critique aims to appraise the need for focused research, in order to develop clinical and policy decisions that will guide general medical and palliative care professionals in their care of dying patient. Weighted against this need are tenets that value the practical and ethical challenges of palliative care research as unique and insurmountable. These two perspectives are argued from a null hypothesis that evidence-based research needs not violate the physician’s duty of care to his or her patients and may take place with the express intent of achieving symptomatic relief for both the present subject and future patients. The subjective nature of effective palliation is at the crux of the discussion; the text stresses recurrent themes in patient’s view on palliative care. For instance, many dying patients value autonomy, spiritual guidance, psychosocial support, and symptom relief, as well as the involvement of, and support for, their families.

2.17.2 Late Presentation and Late Diagnosis: In practice patient present late when disease is already complicated and degenerated thus leading to late diagnosis. In many development countries, patients often present with incurable condition at diagnosis. This is due to belief that the disease is due to spiritual forces and discourage from seeking medical assistance and this makes them to resort to complementary and alternative medicine. For this reason, some palliative care systems have incorporated traditional healers in their education programme in order to gain community acceptance and facilitate palliative care delivery.

2.17.3 Underdeveloped pain management: Although there are no national prevalence statistics about pain in Nigeria, we find that many terminally-ill patients have pain, and this constitutes a

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major health problem. Effective pain management and control is a very vital facet of palliative care as unrelieved pain affects both quality of life and the will to live among these patients. Poorly managed pain will lead to poor quality of palliative care provided. There are difficulties encountered in diagnosis of pain in our environment. In many developing countries like Nigeria, the prevalence of pain at the time of diagnosis is between 50% and 75%. Uganda is only the third African country to have made morphine available and affordable to its patient population. The several challenges facing effective pain relief in practice are similar to those of other developing nations and include drug availability, lack of referrals, fears of misuses of potent narcotics/under-prescribing, lack of public awareness (healthcare workers, policymakers/administrators, the public), cultural and religious beliefs. Shortage of financial resources, limitations of healthcare delivery systems and personnel, absence of national policies on pain relief and palliative care and legal restrictions on the use and availability of opioid analgesics.

2.17.4 Applied theories: Structural functionalism by Herbert Spencer and Emile Durkhelm in 19th century, delves on the understanding of society that views social system as collective means to fill social needs. There are a number of activities that need to be carried out to ensure that certain needs are fulfilled. This theory sees institutions as being interlinked in society and thereby take into consideration the network of relationship that exists between these institutions. Society is also viewed as constantly striving to be at a state of equilibrium. The palliative care of terminally ill patients cannot be looked at in isolation, given their interconnectedness to psycho-social support and family integration.

Society is compared to the human body, just as the structural parts of the human body function independently to help the entire organism survive, social structures work together to preserve society. Thus, the regulatory environment within which palliative function must be such that the well-being of the terminally-ill must be of paramount importance at all times; hence psycho-social support and family integration provide the yardstick within which the variables of palliative care process are measured.

Symbolic interactionism which was invented by Blumer (1999) considers the self to reflect society and organise behaviour that addresses the nature of human interaction, and the relationship between society and the person. The society itself is interaction, it does not exist, but rather created and goes through dynamics as persons interact. Since thought can be used to anticipate the effectiveness of alternative courses of action in resolving problems, social interaction is thus literally constructed. Palliative care do not exist in a vacuum, what makes this

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possible and valuable is the interaction and suitability to the terminally-ill. On the other hand, psycho-social support and family integration are stand alones as individual social subsystems with unique and distinctive characteristics, what however, gives them value and distinctiveness is the synergy and flavour palliative care provide.

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CHAPTER THREE

METHODOLOGY

3.1 Research design

The research design adopted for this study was the descriptive survey research design of the *ex-post facto* type. This is chosen because it provides the researcher the opportunity to collect data without manipulation of the independent variables which had already occurred.

3.2 Population of the study

The population of the study was 587 and were in three categories and comprised 202 terminally-ill patients from wards and clinics as well as 202 family caregivers representing one family caregiver for one patient while the third category were the health workers made up of doctors, nurses social workers and physiotherapists selected also from the same wards and clinics totalling 183 health workers. Total respondents for the study were 587.

3.3 Sample and sampling technique

The study adopted proportionate, stratified and purposive sampling procedures to ensure actual representation of respondents from the three categories. i.e Health workers, patients and family caregivers. The health workers were stratified into four strata based on their professions (doctors, nurses, physiotherapists and social worker). Sixty percent of the total population of health workers' category were chosen from each stratum because they constituted a good representation in the health workers category.

From the chosen eight wards and three out-patients clinics, 202 terminally-ill patients were chosen excluding the unconscious patients in each of the chosen wards. The same applies to their family care-givers selected at the ratio of one family caregiver to one patient (202 respondents each from the two categories).

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Wards and Clinics used for the study

Wards / Clinics	**Ward / Clinics Code**	**Health Workers**					**Family Care-Givers**	**Patients**
		Doc	**Nurse**	**Physio**	**SW**	**Total**		
Radiotherapy Ward	RTH	6	10	2	2	20	23	23
Radiotherapy Clinic	RTH Clinic	4	6	2	3	15	31	31
Surgical Out Patient	SOP	6	9	3	2	20	31	31
Medical Out Patient	MOP	6	8	2	3	17	30	30
West West One	WW1	4	7	2	3	13	20	20
South West Four	SW4	4	6	2	3	15	10	10
South East Two	SE2	5	7	3	2	16	13	13
West Three	W3	3	5	2	2	12	12	12
West West Two	WW2	4	6	2	2	10	12	12
East Two	E2	4	5	2	2	12	10	10
East One	E1	3	7	2	2	12	10	10
Total						**183**	**202**	**202**

3.4 Instrumentation

The data for this study was collected using three separate instruments for patients, health workers and family care givers. The instruments were psychosocial support scale for the terminally ill, family integration scale for the family care givers and palliative care services scale for the health workers. These were complemented with In-depth. Interview (IDI), using subthemes of psychological support, social support and family integration for all the three categories of respondents.

Psychosocial Support Scale

Section A focused on the socio-demographic background of the patients, family care givers and health workers. This includes age, marital status, sex, occupation, religion, and duration of illness

Section B was a 20 item scale on psychosocial support of the terminally ill. It was adapted from multi-dimensional scale of perceived social and psychological support by Zimet, Dahlem and Farley (1998), drawn on a modified 4-point scale of strongly agree, agree, disagree

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and strongly disagree, each carrying the weight of 4, 3, 2 and 1, respectively. Some of the items were restructured to suit the purpose of the study.

In perceived psycho-social support validity study, construct validity, content validity and criterion related validity were ensured. The same group of patients both in-patients and out-patients were repeatedly used and their data were consistent to ensure reliability. In this connection an internal consistency reliability of 0.67 was obtained.

Family Integration Scale

This was an 18 item instrument that utilises family integration in palliative care (FIPCQ). It seeks information on the burden of care on the family care givers. It was adopted from Family Strain questionnaire by Robinson and Thumer (2000). The items were drawn on a 4 point scale of Strongly Agree, Agree, Disagree and Strongly Disagree, each carrying the weight of 4,3,2 and 1 respectively.

Three instruments have been previously used in validating the family disruption from illness. The concurrent validity of the previously used instrument was generally good. Thus, it emphasises its ability to measure the family involvement in palliative care.

The correlation co-efficient of the previous studies were reliable. However, family disruption from illness correlated significantly in the expected direction, thus ensuring its reliability. Hence 0.65 was obtained for reliability co-efficient.

Palliative Care Services Scale

This comprises of 15 item instrument on health care as perceived by the health workers in palliative care (HWPPCQ). It was adapted from palliative care evaluation tool kit by Weissman (1999). The items were drawn on a four point scale of: Strongly agree, Agree, Disagree and Strongly disagree. Each carried the weight of: 4, 3, 2, and 1, respectively.

The palliative care tool kit relied solely on existing literature which was also selected from the existing tools and the professionals in the palliative care were frequently used to review the item through pre and pilot testing procedures to ensure validity. The test- retest reliability showed the desired standard, thus confirming its reliability, and 0.71 was obtained

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3.5 In-depth-Interview

The qualitative method of in-depth interview (IDI) was used to complement the questionnaires in order to ensure a more comprehensive information from respondents that could not be revealed by the survey technique. The in-depth interview affords opportunity for mutual interaction of the researcher with respondents. A total of 10 IDI sessions were conducted with the representatives from the three categories of the respondents used for the study. This was done making use of discussion guide and tape recorder to store up the responses asides the note taking. The in-depth-interview guide is in appendix 1.

Table 3.1: List of IDI Sessions Conducted for the Study

Ward/Clinic	Designation of Respondents	No of sessions	Date conducted	No of Respondents
Radiotherapy ward	Physiotherapist	1	8/10/2013	1
Radiotherapy Clinic	Patient Family Caregiver	1 1	8/10/2013 8/10/2013	1 1
Surgical Out patient (SOP)	Patient Family Caregiver	1 1	15/11/2013 15/11/2013	1 1
South West Two	Doctor	1	27/9/2013	1
East One	Nurse	1	19/12/2013	1
East Two	Social Worker	1	19/9/2013	1
Medical Outpatient	Doctor	1	5/11/2013	1
West West One	Nurse	1	14/12/2013	1
		10		10

Sub Themes of IDI

1. Perception of the three categories of respondents on palliative care
2. Psychological support and palliative care
3. Social Support and palliative care
4. Family integration and palliative care

3.6 Translation of Protocol to Local Languages

The questionnaires were translated into Yoruba language for the patients and family care givers that do not understand English language to enable them participate in the study.

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3.7 Administration of Instrument

An introductory letter was obtained from the researcher’s Head of Department and Co-Supervisor. Prior to securing the introductory letter, a copy of the proposal was presented to the UI/UCH Ethical Committee for approval, which was given after necessary corrections were effected on the research protocol. The questionnaires were then distributed by the researcher and four research assistants from the study area who would have been familiarized with the appropriate instructions. The instruments were complimented with In-depth Interview (IDI) for the three categories of respondents. The participants for the IDI were selected from the three categories of respondents, each professional in health worker category was represented. Same number of patients and family caregiver were interviewed.

3.8 Method of Data Analysis

The data collected were analysed using descriptive statistics of simple percentages and bar charts for the demographic data while multiple regressions and Pearson’s product moment correlation was used for research Objectives and hypotheses. Content analysis was used for the In-depth-interview. Findings in IDI were documented and used to support literature in the discussion of findings.

3.9 Ethical Consideration

Due to the nature of this research, the life threatening disease condition s require some moral restraint in order not to violate individuals’ rights. Thus, ethical approval was sought from relevant institutional authorities i.e UI/UCH ethical committee which was approved. Informed consent was also obtained from the participants in the study.

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CHAPTER FOUR

RESULTS AND DISCUSSION OF FINDINGS

This chapter deals with the results and discussion of findings based on the information collected from the 587 respondents used for this study. The results obtained were clearly presented and exclusively discussed starting with the demographic status of the respondents in part “A”. Furthermore, results of the analysis of quantitative data on the three hypotheses and two research questions were presented in tabular forms followed by detailed discussion in part “B”. These were complemented with report from the qualitative data obtained from in-depth-interview.

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PART A:

This part of chapter four presents the demographic characteristics of the respondents such as the respondents’ age, marital status, gender, and religion.

4.1 Demographic characteristics of the respondents:

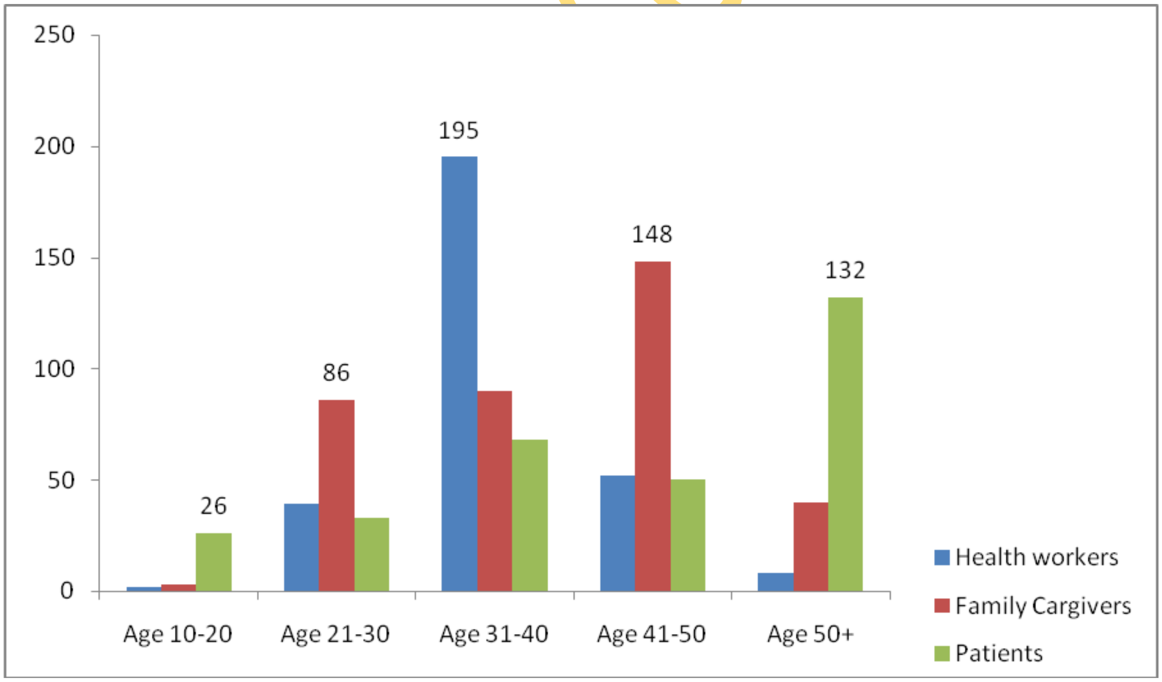
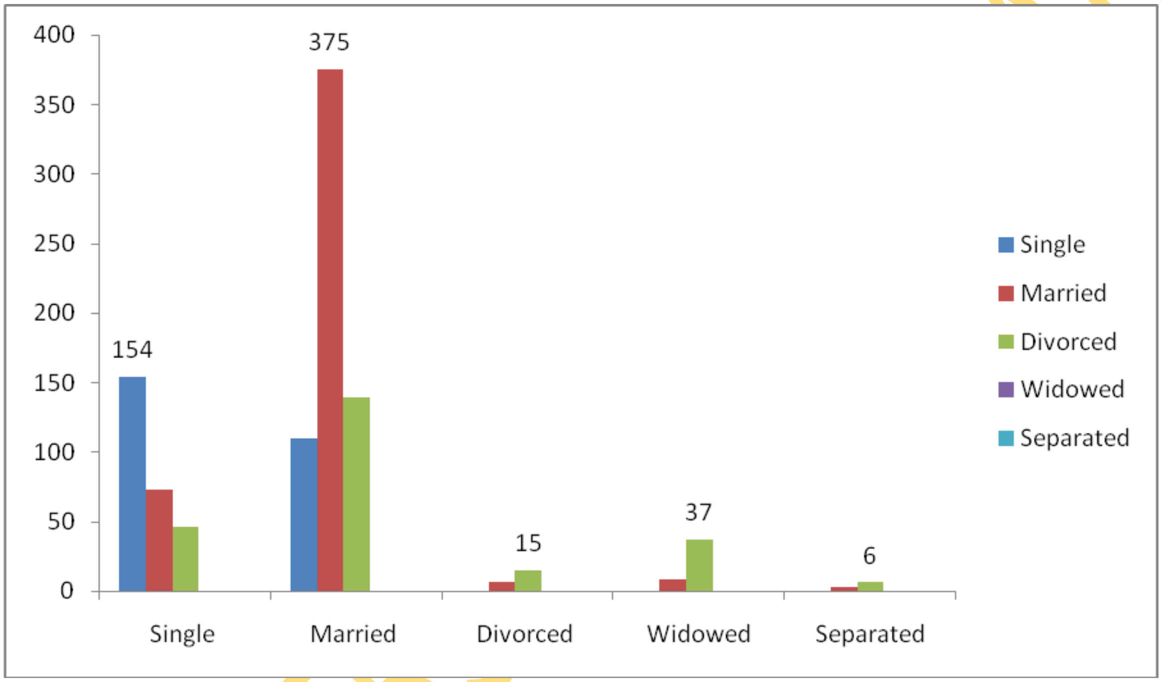


Fig 4.1: Bar chart showing the distribution of the respondents by age.

Figure 4.1 above shows the distribution of the respondents by age. It shows that the three categories of respondents (Health Workers, Family Caregivers and Patients) between the age bracket of 10-20years were 26 or 4.4% while those between the age range of 21 to 30 years were 86 or 14.6%. Similarly, the respondents between the age range of 31 to 40 years were 195 or 33.2% while those in the age bracket of 41 to 50 years were 148 or 25.2%. The respondents aged 50 and above constituted 132 or 22.4% of the respondents used for this study. The respondents between the age range of 31years and above constituted the majority population used for this study. The majority of the patients used for this study fell between the age range of 31years and above.



Figures 4.2: Bar chart showing the distribution of the respondents by marital status

Figure 4.2 above shows the bar chart of the distribution of the respondents' marital status (health workers, family caregivers and patients). This revealed that majority of the participants were married 375 (63.8%), 154 (26.2%) were single; 37 (6.3%) were widowed and 6 (1.2%) were separated.

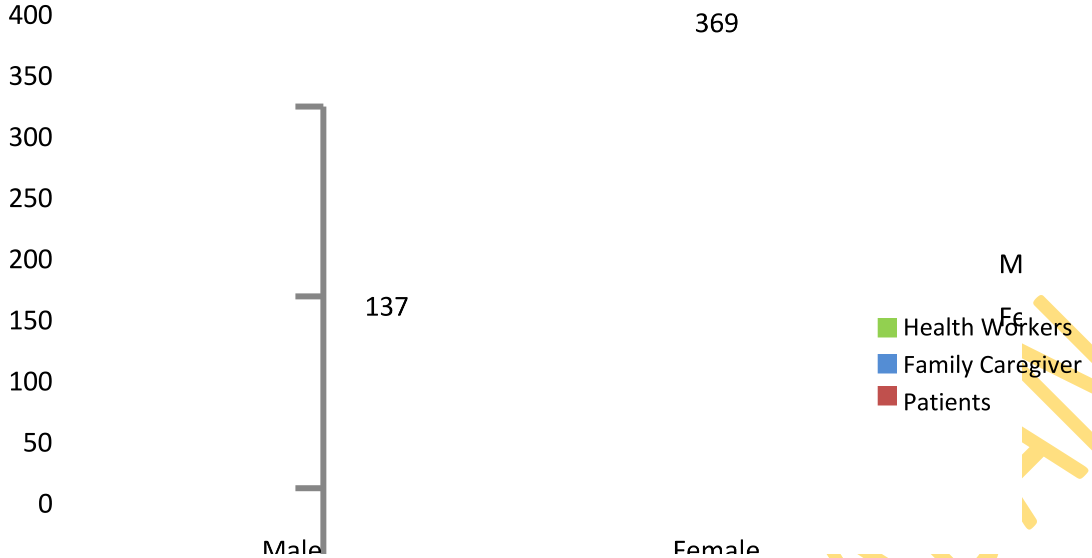


Figure 4.3: Bar chart showing the distribution of the respondents by gender

Figure 4.3 above shows the bar chart of the distribution of the respondents' gender (health workers, family caregivers and patients). The figure shows that 218 or 37.1% respondents were male while 369 or 62.8% of the total respondents were female. It can also be seen from figure 3 above that the majority of the respondents used for this study were females that is the health workers, family caregivers and even the patients. The female health workers and family care givers constituted the majority respondents.

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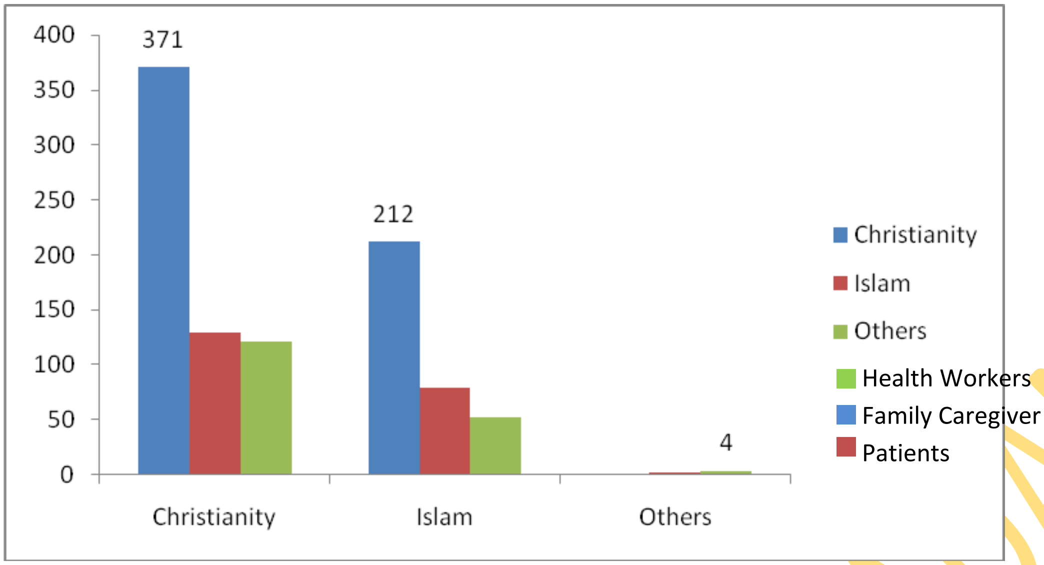

Figure 4.4: Bar Chart showing the distributions of the Respondents by Religion.

Figure 4.4 above shows the bar chart of the distribution of the respondents by religion (health workers, family caregivers and patients). The figure shows that the adherents of Christianity used for this study were 371 or 63.2% while Muslims were 212 or 36.1%. The figure further shows that the adherents of other religions were 4 or 0.6%. The majority of the respondents used for this study were the adherents of the two most popular religions in the location of the study (South West Nigeria) but it is interesting to note that the adherents of other religions are identifiable among the health workers, family caregivers and the patients used for this study.

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Part B: Presentation of the Results on the Test of Contributions and Strengths of the Relationship between the Independent and Dependent Variables.

This section of chapter four deals with the presentation of the result pertaining to the test of prediction and extent of contribution of the independent variables on the dependent variable as well as their strength of the relationship. The presentations were done on the basis of each research question and hypothesis raised. Each result and finding is clearly presented in table form followed with interpretations and detailed discussion. The raw data of the joint prediction of psychological support was presented in appendix iv.

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4.1 Perception of terminally ill patients, family caregivers and health workers on palliative care

This portion deals *with the examination of perception of the terminally ill, family caregivers and health workers on palliative care as raised by objective one* which examined the perception of the three sets of respondents used for the study on palliative care. This was obtained by the responses of the three categories which were calculated using mean scores and weighted mean $\overline{X}$ of the three sets of respondents. This was done in three parts; each for the three categories of respondents

(A) The Terminally ills:

Table 4.1a: Mean scores of the perception of terminally ill patients (psychosocial support and family integration) on palliative care

S/N	Psycho-Social Support	SD	D	A	SA	Mean	S.D
1	There is a special person who is around when I am in need.	2 1.0%	16 7.9%	85 42.1%	99 49.0%	3.39	.68
2	There is a special person with whom i can share my joys and sorrows.	1 1.5%	16 7.9%	96 47.5%	89 44.1%	3.35	.65
3	My family really tries to help me.	2 1.0%	7 3.5%	112 55.4%	81 40.1%	3.35	.60
4	I find peace in my place of worship.	9 4.5%	11 5.4%	87 43.1%	95 47.0%	3.33	.77
5	I get the emotional help and support I need from my family.	2 1.0%	11 5.4%	120 59.4%	69 34.2%	3.27	.60
6	I can talk about my problems with my family.	4 2.0%	12 5.9%	115 56.9%	71 35.1%	3.25	.65
7	Have a special person who is a real source of comfort to me.	3 1.5%	21 10.4%	103 51.0%	75 37.1%	3.24	.69
8	There is a special person who is a real source of comfort to me.	5. 2.5%	15 7.4%	108 53.5%	74 36.6%	3.24	.70
9	I have support in what I do.	7 3.5%	16 7.9%	127 62.9%	52 25.7%	3.11	.68
10	I am happy about my relationship with other family members.	11 5.4%	24 11.9%	111 55.0%	56 27.7%	3.05	.78
11	My family is willing to help me make decisions.	8 4.0%	24 11.9%	127 62.9%	43 21.3%	3.01	.70
12	I have understanding of my present condition.	9 4.5%	42 20.8%	102 50.5%	49 21.3%	2.95	.70
13	I have information that helps me overcome my difficulties.	12 5.9%	54 26.7%	109 54.0%	27 13.4%	2.75	.76
14	I can face my problems.	10 5.0%	74 36.6%	93 46.0%	25 12.4%	2.66	.76
15	I have friends with whom I can share my joy and sorrow.	19 9.4%	73 36.1%	86 42.6%	24 11.4%	2.57	.82
16	I have financial problems.	21 10.4%	68 33.7%	90 44.6%	23 11.4%	2.57	.83
17	I can talk about my problems with my friends.	17 8.4%	74 36.6%	95 47.0%	16 7.9%	2.54	.76
18	My friends really try to help me.	17 8.4%	77 38.1%	92 45.5%	16 7.9%	2.53	.76
19	I can count on my friends when things go wrong.	17 8.4%	95 47.0%	72 35.6%	18 8.9%	2.45	.77
20	I feel I am a burden to my friends.	37 18.3%	77 38.1%	71 35.1%	17 8.4%	2.34	.87

Weighted $\bar{x}$ = 3.14

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Interpretation and discussion:

The rating of the perceptions of the respondents on the Psychosocial-Supports and family integration on palliative care for the terminally ill patients are shown on table 4.1a on the previous page. The summary of the ratings goes thus:

"There is a special person who is around when I am in need" (Mean = 3.39) ranked highest by the mean score and was followed by "there is a special person with whom I can share my joy and sorrows" (Mean =3.35), "My family really tires to help me (Mean = 3.35). "I find peace in my place of worship" (Mean =3.33). "I get the emotional help and support I need from my family" (Mean =3. 27). "I can talk about my problems with my family" (Mean = 3.25) "I have a special person who is a real source of comfort to me" (Mean = 3.24). "There is a special person in my life who cares about my feelings" (Mean = 3.24). "I have support in what I do" (Mean = 3. 11), "I am happy about my relationship with other family members" (Mean =3.05), "My family is willing to help me make decisions" (Mean 3.01). "I have understanding of my present condition" (Mean =2.95). "I have information that helps me overcome my difficulties" (Mean = 2.75). I can face up to my problems (Mean = 2.66), "I have friends with whom I can share my joys and sorrows" (Mean = 2.57). "I have financial problems" (Mean = 2.57). "I can talk about my problems with my friends" (Mean = 2.54). "My friends really try to help me" (Mean 2.53). "I can count on my friends when things go wrong" (Mean 2.45) and lastly by "I feel I am a burden to my friends" (Mean 2.34) respectively weighted mean assumed for 3.14.

It must be noted that only the 202 terminally ill patients' respondents used for this study responded to various question statements asked. The mean (X) scores were determined and the weighted average mean was calculated. In the table 4.1 above, all the 20 items listed obtained high mean scores of between 2.34 and 3.39 out of a maximum score of 4.00. These X scores are high signifying that the respondents (patients) have positive opinions about the psychosocial supports and family integrations. The weighted X score of 3.14 also attested to the fact that psychosocial supports and family support and family integrations enhanced the palliative care offered to terminally ill patients.

Out of 20 item questions for the terminally ill on their perception of palliative care item no 9 which that states" I have support in what I do" carried the highest percentage of 62.9% i.e (127 respondents) while item no 5 " I get the emotional help and support I need from my family carried 59.4% (i.e 120 respondents), Item 13 however states that "I have information that helps

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me overcome difficulties carried 54% (i.e 109 respondents), however, item 16 and 18 carried the highest standard deviation of .87 and .82 respectively, confirming the importance of various types of support in palliative care, the holistic nature of the care, (WHO, 2002) interdisciplinary approach in palliative care (Seymour, Clark 2003, psychological effect that terminal illness could have on the sufferer (Brazil, Howell, & Bednard 2005). The highest mean score between 2.34 and 3.39 accounted for the positive significance of the above items on the outcome of this study.

In line with the above. Blanch (2000) and Holloway, (2003) argued that, palliative care requires a multidisciplinary approach to be effective. Such approaches include psychological and social supports as well as family integration in order to achieve effective palliative care services for the terminally- ill persons. In the same vein, Tanchel (2003) stated that, the family of the terminally- ill patient is at the centre of the unit of care and their supports and education are vital because losses suffered by the patients will be experienced by the family. Hence, Davies and Steele (1995) argued that, it is important to give family members opportunities to talk as individuals as well as in groups, regarding the palliative care services provided to their loved ones.

The above findings also support the literature that palliative care is an approach that improves the quality of life of patients facing problems associated with life threatening illness and their families through prevention and relief. To further buttress the influence of psychosocial support and family integration on palliative care, this study revealed a weighted mean and 3.4 out of maximum mean (X) of 4.0. this implies that the perceptions of the total respondents were high over the influence of psychosocial support and family integration. This finding was in line with the submission of Morrow (2011).

> *“Palliative care with supports are activities that aim to enhance the quality of life of patients and their families who are faced with serious debilitating illness, it also focuses on clear communication, advance planning and coordination of care”*

This study also attested to the fact that effective palliative care for the terminally ill require all supports including the moral and family integration which support the argument of WHO (1998) that:

> *Effective palliative care requires a broad multidisciplinary approach that includes the family and the use of available*

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community resources that can successfully be implemented even
if resources are limited

It is impossible for the individual with the diagnosis of terminal illness to cope alone, his/her problem automatically becomes the concern of family member. Seeking health care, thus, requires that significant person (s) in the family accompanies the patient to the hospital; every attempt to make them feel isolated is reduced as much as possible. Again, the holistic approach in palliative care encompasses the multidiscipline's involvement in their care, hence, doctors, nurses, social workers, physiotherapists and spiritualist have a stake in their effective management to relieve suffering, and improve psychological effect that illness would have caused them. This is in line with the submission of Isabelle (2009) that psychological support for the terminally- ill should be part of comprehensive programming, and not a stand alone service, the interventions should include a variety of approaches such as counselling, family therapy and succession planning.

Perception of palliative care by the terminally ill patients used for this study attested to the fact that opportunity to involve significant others in their management relieves them of the burden of feeling dejected and improves their quality of life.

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(B) The Family Caregivers:

The perceptions of family caregivers on palliative care of terminally ill patients as raised by objective 1 which examined the perceptions of the family caregivers on the palliative care.

Table 4.1b: Mean scores of the perceptions of the family caregivers on palliative care of the terminally ill patients

S/N	Family Support	SD	D	A	SA	Mean	S.D
1	His/Her ailment has caused some emotional disturbance.	3 1.5%	30 14.9%	114 56.4%	55 27.2%	3.09	.69
2	Caring for Him/Her has altered my personal plans.	7 3.5%	36 17.8%	93 46.0%	66 32.7%	3.08	.80
3	His/Her ailments has created alteration in the family's role performance.	16 7.9%	38 18.8%	77 38.1%	71 35.1%	3.00	.93
4	The care positively influences His/Her well-being.	15 7.9%	23 11.4%	119 58.9%	45 22.3%	2.96	.80
5	I am really prepared to take care of Him/Her.	10 5.0%	32 15.8%	118 58.4%	42 20.8%	2.95	.75
6	His/Her Illness has caused financial constraints.	4 2.0%	54 26.7%	95 47.0%	49 24.3%	2.94	.77
7	I prefer to care for Him/Her in the hospital.	25 12.4%	47 23.3	55 27.2%	75 37.15	2.89	1.05
8	Caring for Him/Her is restrictive.	20 9.9%	56 27.7%	90 44.6%	36 17.8%	2.70	.88
9	I have sleep pattern disturbance.	34 16.8%	55 27.2%	81 40.1%	32 15.8%	2.55	.95
10	He/She exhibits altered behavioural pattern.	23 11.4%	78 38.6%	75 37.1%	26 12.9%	2.51	.86
11	I have heard of palliative care before.	37 18.3%	63 31.2%	73 36.1%	29 14.4%	2.47	.95
12	I get easily tired as a result of caring for Him/Her.	21 10.4%	84 41.6%	82 40.6%	15 7.4%	2.45	0.78
13	Caring for Him/Her has been convenient.	29 14.4%	87 43.1%	73 36.1%	13 6.4%	2.35	.80
14	His/Her illness has caused me a feeling of resentment.	26 12.9%	91 45.0%	73 36.1%	12 5.9%	2.35	.78
15	Palliative care is meant for those nearing end of life.	52 25.7%	63 31.2%	56 27.7%	31 15.3%	2.33	1.02
16	I prefer to care for my patient at home.	55 27.2%	67 33.2%	55 27.2%	25 12.4%	2.25	.99
17	Other family members have dumped His/Her care to me.	43 21.3%	84 41.6%	62 30.7%	13 6.4%	2.22	.86
18	My financial resources are adequate to pay hospital bill.	36 17.8%	107 53.0%	47 23.3%	12 5.9%	2.17	.79

Weighted $\bar{x}$ = 3.10

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Interpretation and discussion:

The rating of the perception of the responses of the family caregivers on the palliative care services of the terminally ill patients are shown on table 4.1b on previous page. The summaries of the ratings goes thus:

“His/Her ailment has caused some emotional disturbance” (Mean = 3.09) was rated highest by the mean score and was followed by “Caring for Him/Her has altered my personal plans” (Mean= 3.08), His/Her ailments has created alteration in the family’s role performance (Mean = 3.00). “The care positively influences His/Her wellbeing” (Mean =2.96), “I am really prepared to take care of Him/Her” (Mean =2.95), “His/Her illness has caused financial constraints” (Mean =2.94), “I prefer to care for Him/Her in the hospital” (Mean =2.89), “Caring for Him/Her is restrictive” (Mean =2.70), “I have sleep pattern disturbance” (Mean 2.55), “He/She exhibits altered behavioural pattern” (Mean =2.51), “I have heard of palliative care before” (Mean =2.47), “I get easily tired as a result of caring for Him/Her” (Mean = 2.45), “Caring for Him/Her has been convenient for me” (Mean =2.35), “His/Her illness has caused me a feeling of resentment” (Mean =2.35), “Palliative care is meant for those nearing end of life” (Mean =2.33), “I prefer to care for my patient at home” (Mean =2.25), “other family members have dumped His/Her care to me” (Mean =2.22) and lastly, by “My financial resources are adequate to pay hospital bill” (Mean =2.17).

Table 4.1b above further shows the respondents’ degrees of opinions on the research question two above. It must be mentioned that 202 family care givers used for this study responded to all the 18-items question statements raised. The X scores were determined and the weighted average X was calculated. In the table, all the 18 items listed obtained high X scores of between 3.09 and 2.17 out of a maximum score of 4.00. These X scores are high, implying that all the respondents (family caregivers) perceived caring for their terminally ill relations differently. For example while 169 respondents agreed that caring for terminally-ill patients have caused them emotional disturbance, only 33 respondents disagreed. Again, while 143 respondents (family caregivers) disagreed to the fact that they are financially capable of caring and 59 caregivers agree that they can cope financially.

The in-depth interview conducted with one of the family caregivers revealed that:

> *I see palliative care for my relation as an appropriate and effective type of management which has helped him and we his children in so many ways. There is clear communication between the health care team the family and the patient. This allows us to*

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> *express what my Dad's feelings were and also our anxieties were frequently reassured about his health the details of all stages of management were explained. This, of course, had a positive impact on his health moreso that his wife and children are giving him support as required and the health workers have been wonderful. Its like a home away from home.*

It could be inferred from different perceptions of the family caregivers that caring for terminally ill patients is traumatic, burden-some, hopeless, stressful, resentful and problematic. In connection with the above, Monroe (1999) warns that the caring and diagnosis of terminally-ill persons is traumatic for everyone, hence the knowledge and understanding of the crisis are important as the patients' realities change within seconds. In the same manner, Baker and Teno (2000) stressed that supporting patients and other family members with redefining requires that health care providers appreciate how difficult it is for family members to care for their terminally-ill loved ones. In this sense of reality, Kissan & Kenzie (2003) advised that: "when former patterns are no longer feasible, health workers should help them to consider adjustments or alternatives".

Again, the nature of palliative care is to ensure both psychological and social aspects of care for the terminally-ill in which assistance in every area should be rendered for the loved one. Hence, good grooming and overall care help in health promotion, improves quality of life and ensures dignity (Jeffery, 2003). But Tanchel (2003) argued that after the supports have been provided by all concerned, even if the inevitable (death) happens, the good memory of how the loved one has been taken care of them will help the family member cope better in their bereavement. To buttress the above findings, another family caregiver said that:

> *Ever since my mother's illness started, I had to leave Lagos to come and assist in her care. I never knew what she described to me as a "lime sized boil" could result into her having a major operation done. She was counselled and I saw that she had a strong will and was quite positive that all would be well with her. I am really prepared to support and take care of her. When we got to the stage of her having to commence chemotherapy, we could afford four courses out of the eight courses that were prescribed for her. We then had to ask other significant family members for financial assistance which they responded to within the limits of what they could afford. We are just trusting God for my mum's gratuity to be ready before we exhaust the funds we have at present.*

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The above findings reveal further that integrations of the efforts of the family caregivers with those of the palliative care for the ill persons adequately reassured the patients themselves. Hence, Tanchel, (2003) argued that:

> *the family integrated components to terminal patient care allows the patient not be treated as individual with problems and symptoms, but also as a family member whose reactions interlock with the support system (p 121).*

Again, Davies & Steele (1995) buttressed the above that, family members must be given opportunities to talk as individuals as well as in groups regarding the palliative care(s) for their loved ones. To show how important the efforts of the family members are at enhancing the palliative care for the ill patients, WHO (2002) stressed that palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life threatening illness. Again, Soyanwo (2004) opined that palliative care is the active holistic care of patients with advanced progressive illness, management of pain, provision of psychological, social, spiritual and moral supports. In summary, Bolen (1999) and Canto-Grace (2007) in separate studies made us realise that supports can come from varieties of sources for the terminally-ills such as: the family, friends, romantic partner, pets, community ties and co-workers.

Out of the 18-item questionnaire for the family caregivers, item 4 and 5 carried the highest percentage of 58.9% and 54.4%, respectively, in response to the statements " the care positively influences her well-being and " I am really prepared to take care of him" followed by item 1 that states "Her ailment has caused some emotional disturbance" 56.4%. These are in keeping with the positive influence of the family. In palliative care, quite a significant number were really prepared to take care of their terminally-ill relatives, they are emotionally attached. David & Steele (2000) expressed that wisdom being passed on to their loved ones, helps family members to communicate what they might not be able to verbalise to their loved ones (Andershed 2004), writing of an ethical will could thus, be given consideration. The last item (18) which states that "My financial resources are adequate to pay hospital bill". Over 50% family caregivers disagree with this statement, they are the ones in the eye of the storm, they go around from one end to the other end, they are well informed about the financial implication the illness has on them. So the submission of Olievere (1990), is in support of this fact that the family caregivers have to deal with poverty, unemployment and poor housing brought about by

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the terminal illness of their loved ones. Fraser's (2002) belief is that help has to be sought from voluntary agencies and philanthropist who can assist.

(C) The Health Workers:

What is the perception of health workers on the palliative care as raised by research objective 1 of the study which examined the perception of the health workers on palliative care of the terminally-ill?

Table 4.1c: Mean scores of the perception of Health workers on the palliative care for the terminally ill patients.

S/N	Palliative Care Services	SD	D	A	SA	Mean	S.D
1	Palliative care should be the standard medical treatment for patients who are suffering from a terminal illness.	1 .5%	6 3.0%	64 31.7%	131 64.9%	3.61	.58
2	Pain medication should be given as needed to terminally ill patients.	3 1.5%	4 2.0%	73 36.1%	122 60.4%	3.55	.63
3	Spiritual care should include counselling the terminally-ill patients.	4 2.0%	15 7.4%	91 45.0%	92 45.5%	3.32	.70
4	Patients should be maintained in a pain free state.	13 6.4%	13 6.4%	87 43.1%	89 44.1%	3.25	.83
5	Patients should have the right to determine their own degree of medical intervention.	6 3.0%	29 14.4%	100 49.5%	67 33.2%	3.13	.75
6	Patients have the right to determine their own degree of psychosocial intervention.	6 3.0%	30 14.9%	95 47.0%	71 35.1%	3.13	.77
7	Complete pain relief is a reasonable goal even when the pain is not caused by a terminal condition.	12 5.9%	29 14.4%	103 51.0%	58 28.7%	3.01	.80
8	Addiction to oral morphine is not a serious issue given that terminally-ill patients have a short time to live.	17 8.4%	45 22.3%	94 46.5%	46 22.8%	2.81	.87
9	Opening discussions of end of life care should be deferred until there is no further effective curative treatment available.	31 15.3%	58. 28.7%	66 32.7%	47 23.3%	2.61	1.00
10	Pain at the end of life is an inevitable part of the dying process.	44 21.8%	61 30.2%	65 32.2%	32 15.8%	2.42	.99
11	As a rule, terminally-ill patients prefer not to talk about death and dying.	34 16.8%	91 45.0%	66 32.7%	11 5.4%	2.28	.80
12	I do not like talking about death and dying with patients.	41 20.3%	82 40.6%	65 32.2%	14 6.9	2.27	.86
13	The most appropriate person to make end of life decisions is the patients primary care provider.	44 21.8%	83 41.1%	55 27.2%	20 9.9%	2.25	.90
14	Estimation of pain by a Health worker is a more valid measure of pain than patient's self report.	57 28.2%	101 50.0%	33 16.3%	11 5.45	2.01	.83
15	A patient should experience discomfort prior to receiving the next dose of pain medication.	72 35.6%	85 42.1%	31 15.3%	14 6.9%	1.92	.87

Weighted $\overline{x}$ = 3.21

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Interpretation and discussion:

The perceptions of the health workers on the Palliative Care for the terminally-ill patients are shown on table 4.1c above. The summaries of the ratings are as follows:

"Palliative care should be the standard medical treatment for patients who are suffering from a terminal illness" (Mean=3.61) was ranked highest by the mean score and was followed by "Pain medication should be given as needed to terminally-ill patients". (Mean=3.32). "Patients should be maintained in a pain free state" (Mean=3.25). "Patients should have the right to determine their own degree of medical intervention" (Mean=3.13), "Complete pain relief is a reasonable goal even when the pain is not caused by a terminal condition" (Mean=3.01), "Addiction to oral morphine is not a serious issue given that terminally-ill patients have a short time to live" (Mean=2.81), Opening discussions of end of life care should be deferred until there is no further effective curative treatment available (Mean=2.61), "Pain at the end of life is an inevitable part of the dying process" (Mean=2.42) "As a rule, terminally-ill patients prefer not to talk about death and dying" (Mean=2.28), "I do not like talking about death and dying" (Mean=2.27), "The most appropriate person to make end of life decisions is the patients' primary care provider" (Mean=2.25), "Estimation of pain by a health worker is a more valid measure of pain than patient self report" (Mean=2.01), and lastly that "a patient should experience discomfort prior to receiving the next dose of pain medications" (Mean=1.92).

Table 4.1c above similarly shows the respondents degrees of opinions on the research question one. It must be emphasised that only the health workers (medical doctors, nurses, physiotherapists and social workers) responded to various question statements raised. The X scores were determined and the weighted average was calculated. All the 15 items listed obtained high X scores of between 3.61 and 2.01 out of the maximum score of 4.00. Only item no 15 recorded X score of 1.9 which is less than average. These X scores are high implying that the health workers have positive perceptions about the palliative care provided for the terminally-ill patients.

Out of the 15-item questions on health workers perception of palliative care for terminally-ill, significant percentage of 64.9% (131) believes that palliative care should be the standard medical treatment for patients suffering from terminal illness. Their level of awareness on palliative care is significant. On item 2 that states that pain medication should be given, as needed, to terminally-ill patients, 122 health workers (i.e 60.4%) out of 202 believed that they

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should be maintained in a pain free state as much as possible. This is in keeping with Soyanwo's (2004) definition of palliative care as the active holistic care of patients with advanced progressive illness, management of pain and other symptoms with provision of psychological, social and spiritual supports.

Over 50% health workers also disagree with the statement that health workers' pain estimation is more valid than patient's report. The patient is the most important entity in palliative care and his feelings and worries need to be taken care of. As long as he is not unconscious, the ability to express discomfort is a more reliable report than any health workers' evaluation.

It could be deduced from these perceptions that palliative care services are essential components of comprehensive package of care for people with terminal illness. World Health Organization (2000) buttressed this that, palliative care is an important aspect of care that uses team approach to address the needs of the patients and their family, including bereavement counselling, if indicated. On the care for the terminally-ill by the health workers, Davies (2000) argued that palliative care professionals do help patients find ways, to relieve their sense of burden and to provide patients with opportunities to talk about their fears and concerns and to consider with whom they want to share worries. It can be summed-up that, the major role of the health workers is to provide psychosocial supports to patients and families facing terminal illness.

Furtherance to this, in-depth interview with a doctor reveals that:

> *The central goal of palliative care is relief of suffering. With advanced illnesses that are life threatening, pain is imminent for the sufferer (i.e the patient). So relief of pain becomes a priority, maintaining the patient in a pain free state would help to reduce suffering. Clinical experience has revealed that attending to the psychosocial and medical management of the patients would help in reducing their suffering. The multidisciplinary nature of palliative care helps to see each member in that team as an important entity whose, function in the care of that patient cannot be over estimated.*

On the perception of psychological care, he further stressed that:

> *The spiritual care requires that the doctor, at least for that period of time, identify the patients reverend,*

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> *pastor, imam, traditional priest etc as applicable are involved. The psychological care involves taking care of the psychological pain e.g a parent concerned about who to leave the children with, worried about whether or not they would suffer. The issue of the will needs to be settled and the person who would collect the death certificate needs to be ascertained.*

In the same vein, a Nurse reported that:

> *Patient's quality of life has improved tremendously since the advent of palliative care in this health institution. The terminally ill is not to be regarded as an individual waiting for death sentence, but rather a significant member of a family whose condition affects the smooth running of that family setting. Hence, he/she has the right to correct information about his health, the right to be treated with dignity the right to relief him of suffering, prevent him from agony of pain and accessibility to the different health professionals involved in the patient's care. All these would help improve the psychological, social and spiritual well-being of the patient and family.*

The above findings also lay credence to the argument of Kearney (2000) that the potential for healings in the face of progressive disease is a potential rooted in the special relationship and positive perception between the healer(s) and the sufferers (patients). Brazil, Howell and Bednard (2005) buttressed that the essence of skilled palliative caregivers is to facilitate the caring process through a combination of science, presence, positive perception, openness, compassion, mindful attention to detail and team work.

Palliative care is designed to provide the best quality of life for terminally-ills and their family. Hence, Soyanwo (2004) argued that:

> *"Palliative care is the active holistic care of patients with advanced progressive illness management of pain and other symptoms with provision of psychological, social and spiritual supports".*

In the light of the above, the medical personnel's and their supporting staff and the social workers do not give up and ignore or suspend the care given to the terminally ills. Hence, WHO (2002) said that palliative care is an approach which improves the quality of life of the terminally-ill and their families facing the problem associated with life threatening illness,

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through the prevention and relief of suffering by means of early identification and treatment of pain and other physical, psychosocial and spiritual problems.

The need for up to date knowledge of palliative care among health workers requires that every behaviour the patients put up in the course of caring affects the patient positively or negatively. This is in support of the responses that confirm the submission of Brazil, Howell and Bednard (2005) that it is impossible for any health worker to practise what they do not know and usually traumatic if the thought haunts after the patient dies, but if the terminally-ill patient is under the care of a skilled palliative care personnel, the mere fact that both the patient and the family care giver are struggling to live in the face of progressive debilitating disease, the skill and knowledge of the health worker would make him/her care and support the patients and their family care giver appropriately, thus find meaning and peace in the face of death.

The finding of this study reveals that, palliative care requires more than prescriptions and ingestion of drugs. It can, however, be said that effective palliative care requires that caregivers work cohesively and in collaboration to ensure the physical, social, psychological and spiritual wellbeing of the terminally-ill patients.

From the responses of the three categories of respondents used for this study, it can be deduced that each category has different perception of palliative care while the health workers were concerned about the relief of symptoms for the terminally ill, management of pain, and giving adequate information about expectations as well as possible outcome of illness, their quality of life thus becomes paramount, and this helps to make life bearable for as long as they live. The family caregiver, however, is seen at the centre of care for their ill family member, the extent to which the patient can help himself/herself is limited. So the family caregiver does the running around to ensure things are done appropriately for the patient, ranging from physical care, financial support, ensuring significant family members are well informed about the state of health and necessary assistance sorted as required. They are comfortable with palliative care because it allows flexibility. The patient (i.e terminally-ill), however, is in a state of dilemma as the diagnosis of terminal illness is enough to throw the patient in turmoil. This brings about thoughts of the past, self-esteem and self concept are negatively affected and obviously cannot wade through the stormy waters alone, the multidisciplinary approach of health workers, extremely essential in palliative care, family care giver makes the terminally-ill see himself/herself at the centre of care, and losses suffered by the patient is experienced in parallel

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by the family and in seeking spiritual care, their belief comes to play a vital role in their recovery and existence. This also allows time to pay attention to any unfinished business that might pose problem at the end of life.

4.2 Joint predictions of psychosocial support and family integration on palliative care of terminally ill patients in UCH

This portion of part B in chapter four deals with the joint predictions of the independent variables on the dependent variables and it is anchored on research question one (RQ_2) which states that: *To what extent does psychosocial support and family integration improve palliative care service of the terminally ill patients in UCH?* The data collected from the respondents on this were subjected to multiple regression while the results obtained were presented in tables 4.2a and 4.2b followed by detailed discussion.

Table 4.2a: Joint prediction of psychosocial support and family integration on palliative care of terminally ill patients.

Model	**Sum of squares**	**DF**	**Mean square**	**F**	**Sig.**
Regression	311.661	12	25.972	25.245	.000
Residual	194.438	189	1.029		
Total	506.099	201			

R= .785

R^2 = .616

Adj R^2 = .591

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Table 4.2b Relative predictions of psychosocial support and family integration on palliative care process.

Model	**Unstandarized Coefficient**		**Standardized Coefficient**	**T**	**Sig.**
	B	Std. Error	Beta Contributions		
Psychological support	.507	.113	.376	4.508	.000
Social support	.980	.225	.966	4.345	.000
Family Integration	-.303	.104	- . 755	-2.914	.004.

Interpretation and discussion

It was shown in the table 4.2a above that the joint effect of the three independent variables of psychological support, social support and family integration was significant ($F_{(12.189)}$=25.245 ; R=.785 R^2= .616; Adj. R^2 =.591; p< 0.5). About 62% of the variation in palliative care process was accounted for by the independent variables while the remaining 38% was not due to chance. This, therefore, reveals that palliative care process in UCH, to a large extent, is being determined by the combination of the three independent variables. Also, the result of table 4.2b shows the relative contribution of each of the three independent variables on the palliative care of terminally-ill patients as follows: social support (β= .966, p< .05); psychological support (β= .376, p< . 05) and family integration (β = .755, p< .05). It is noted from the above results that social support predisposed palliative care the most, followed by psychological support and family integration.

The study, like others before it, reveals effect of the three independent variables on palliative care process, hence the combination of all the three independent variables have positive impact on effective palliative care of terminally-ill on relative degrees, This study, therefore, agrees with the submission of Soyannwo (2004) that palliative care is the active holistic care of patients with advanced progressive illness, management of pain and other symptoms with provision of psychological, social and spiritual supports.

This is also supported by WHO (2002) and Soyanwo (2004) that defined palliative care as an approach that improves the quality of life of patients facing the problems associated with life threatening illnesses through prevention and reduction of suffering by early identification, and relief of pain and other problems, be it physical, psychological and spiritual. The finding of

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this study reveals that most of the terminal ill patient identified that the key components to psychological support (Behavioural support, diversional support, counselling services and emotional support) and social support (companionship, spirituality, Regular visitation and Rehabilitative support) were the essential factors that are required by these terminally-ill in order to enhance effective palliative care. Furthermore Hearn, Lakes & Young (2008) views psychological support as helping to build resiliency in both adult and children faced with life threatening / life limiting conditions. It supports families to provide for the physical, emotional, economic, educational and health needs for their loved ones. This, inadvertently, makes them able to understand and deal with the unexpected.

It can also be deduced from the Respondents' responses that paying attention to relief of pain and reducing suffering as well as ensuring other physical, and spiritual well-being would go a long way in ensuring their psychological balance Sheldon (1997) argues that ensuring psychological well-being of the terminally-ill helps to build internal and external resources for them and their families. This, however, helps them to be able to understand and deal with adverse events. The result further showed that the psychosocial support needed by the individual faced with life limiting illness is so paramount that it can never be a stand alone phenomenon, all hands must be the on deck. This is in agreement with Tanchel (2003) when she claims that illness suffered by the patient is experienced also by those significant others who are involved in his care as that ill person becomes the main focus of attention in that environment, losses suffered also would inadvertently affect those close to them. In Lee's (2006) study on controlling patients involvement in decision-making in palliative care, she disagrees that the terminally-ill should be allowed to make decisions on their own, this idea, makes the patient feel irrelevant as they are not given adequate and up-to-date information about their condition and expectation. Hence, whatever instruction they give to them creates a kind of psychological problem for them which would do more harm than the intended good since they are not carried along in decision-making on matters that concern their health.

The purpose of the study was also to identify how psychosocial support and family integration influence palliative care of the terminally-ill. Results, however, showed, that all the components of the independent variables positively correlated with palliative care of the terminally-ill as "having support in what I do" carried the highest percentage of responses among the total respondents of terminally-ill patients used for the study. However, the goal of palliative

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care is to improve quality of life across the illness trajectory through the relief of suffering, including care of the dying and bereavement follow-up Coyle (2002) reported the exact words of a palliative care patient that illness both affects and is affected by all aspects of the individual's being, Kearney (2000) opined that the potential for healing in the face of progressive disease is a potential rooted in the special relationship between the healer and the sufferer. The genuine warm and compassionate relationship of a palliative care or hospice care provider, with his or her patient is frequently a healing relationship.

4.3 Psychological support and palliative care of Terminally ill patients

This portion of the part B of chapter four deals with the examination of the extent to which the components of psychological support contribute to palliative care of terminally-ill patients in UCH. This section is derived from the results presented in the tables 4.3a, 4.3b and 4.3c which were obtained from data collated on the null hypotheses one (HO_1) which states that: *there is no significant relationship between each of the components of psychological support and palliative care of terminally-ill patients.* The data collected from the respondents on this were subjected to multiple regression as well as correlation matrix while the results obtained were followed by detailed discussion.

Table 4.3a Joint predictions psychological support (diversional support, behavioural support, counselling services, emotional support) on palliative care process of terminally-ill patients.

Model	Sum Squares	DF	Mean-Square	F	Sig.
Regression	285.314	5	57.063	50.657	.000
Residual	220.785	196	1.126		
Total	506.099	201	1.126		

R= .751

R^2 = .564

Adj R^2= .553

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Table 4.3b Relative predictions of diversional support, behavioural support, counseling services emotional support and educational counselling on palliative care process.

Model	**Unstandardized Coefficient**		**Standardized Coefficient**	**T**	**Sig.**
	B	Std. Error	B		
(Constant)	.842	555		1.517	.131
Diversional support	-4.649E-02	.101	-.034	-.462	.644
Behavioral support	.275	.086	.204	3.213	.002
Counseling support	.137	.079	.101	1.717	.088
Emotional support	.480	.079	.473	6.034	.000
Educational support	.273	.103	.180	2.659	.008

Interpretation and discussion

It was shown in table 4.3a above that the joint effect of independent variables (diversional support, behavioural support, counselling services, emotional support and educational counselling on palliative care process was significant (F (5.196) = 50.657; R = .751; R^2 = . 564; Adj R^2 = .533; P<. 05) . About 56% of the variation in palliative care process was accounted for by the independent variables while the remaining 44% was not due to chance.

The result above shows diversional support, behavioural support, counselling services and emotional support are good predictors of palliative Care process.

Also, table 4.3b shows the relative contribution of each of the components of psychological support on the dependent: diversional support (β = .473, p<.05); behavioural support (β =.204, p<.05); counseling services (β .180, p<.05) on palliative care process. Hence, while behavioural support, emotional support and educational counselling were significant diversional support and counselling services were not. The finding of this study agrees with Cassel (2000) that the nature of palliative care and the approach of its interdisciplinary team are dependent on the needs of the patient and the resources available, this is also supported by Morrow (2011) that the palliative patient have access to psychological counsel, pain management, fatigue management and rehabilitation. The earlier a diagnosis of terminal illness is made, the better for the patient and his /her family caregiver. Management of symptoms as well as the aforementioned variable are

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brought to bear and in the study followed by systematic mode of management. It gives insight into all aspects of care. Apart from the WHO (2002) definition of palliative care as the active total care of the patients whose disease is not responsive to curative treatment, control of pain, be it psychological, social, the goal, however, includes integrating the psychological and spiritual aspect of patient care. This is supported by the responses of the participants that curative and behavioural therapies have been adopted to relieve them from anxiety, depression and stress. These therapies are able to explore the existing coping strategies and facilitating the development of new ones.

In an in-depth interview with one of the nurses, she had this to say:

> *"Palliative care is regarded as a specialised care, for people with terminal illness. Its focus is to provide relief from the symptoms, pain and stress brought about by the terminal illness. It is appropriate for any age, at any stage of illness and can be provided along with curative treatment. Palliative care utilises a multidisciplinary approach to patient's care in which all the professionals involved perform their tasks for the patient and family. These health professionals come together periodically to formulate a plan of care to reduce suffering in all areas of patient's life and also address physical, emotional, spiritual and social concerns that is brought about by the illness".*

Hearney (1992) reported that guided imagery is another technique used to aid relaxation, and involving them in patient narrative encourages reminiscence by gaining insight into the patients' world. This enhances psychological support for the terminally-ill. Regnard and Kindlen (2001) explained further that a diagnosis of terminal illness and the challenge that a treatment regime presents can lead to distress for the patient as well as family members and friends, availability of palliative care team helps to assess each person and his/her family's situation and, thus, recommend effective ways of managing distress and other emotional and practical consequence of illness. This agrees with the significant result of emotional support, behavioural support and educational support in palliative care.

Additional psychological support can also be given by care givers which serve to complement the ongoing support from families and communities (Fagbenle 2000). The fact also is that this support involved the process of meeting a person's emotional, mental and spiritual needs. The result is also in agreement with the worldwide discovery of health link (2006) that psychological and social supports are processes of meeting a person's emotional mental, and spiritual needs which are the essential elements of positive human development. Conclusively,

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counselling activities for the terminal-ill play a vital role in palliative care practice and is regarded as a confidential discussion between the patients and their care providers. This is indicated at every step of management to make them, able to make informed choices and decision related to the patient's health (ie educational counselling). In the light of this, Babalola (2007) reaffirms that counselling should be part of palliative care in order to help the patient and his family have up to date information about the illness and hence understand the best way to forge ahead in the face of uncertainty.

Table 4.3c Multiple correlation showing the relationship between psychological support (Diversional support behavioural support, counselling services, Emotional support and Educational counselling and palliative care process.

	Palliative care process	Diversional support	Behavioural support	Counselling services	Emotional support	Educational counselling
Palliative care process	1					
Diversional support	.538*	1				
Behavioural support	.500**	.526**	1			
Counseling services	.451**	.522**	.515*	1		
Emotional support	-686**	.690**	.365**	.427**		
Educational counselling	.610**	.476*	.494*	.338**	.657**	1
Mean	9.4554	5.6881	5.8218	5.6535	9.7475	6.6980
S.D	1.5868	1.1576	1.1752	1.1797	1.5647	1.0476

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To also compliment the multiple regression results that showed the contention of each of the components of psychological support, the correlation matrix in table 4.3c revealed that all the five variables had strong positive significant relationship with palliative care with overall mean at 9.45 and standard deviation of 1.58. However the relative correlations were as ranked:

emotional support (r= .686), educational counselling (r=. 610); divisional support (r=.538); behavioural support (r=.510); and counselling services (r=.451).

4.4 Social support and palliative care of terminally-ill patients

This portion deals with the examination of the extent to which the components of social support contribute to palliative care of terminally ill patients. This section is from the results presented in tables 4.4a, 4.4b and 4.4c which were obtained from the data collated on null hypothesis two ($H0_2$) which states that: *there is no significant relationship between each of the components of social support and palliative care of the terminally ill*. The data collected from the respondents on this were subjected to multiple regression as were as correlation matrix while the results obtained were followed by detailed discussion.

Table 4.4a Joint predictions of social support on palliative care process

Model	Sum of square	DF	Mean square	F	Sig.
Regression	131.534	4	32.884	17.295	.000
Residual	374.565	197	1.901		
Total	506.099	201			

R = .510;

R^2= .260;

Adj R^2 =.245

Table 4.4b Relative predictions of social support (companionship, spirituality, rehabilitative support and regular visitation on palliative care process.

Model	**Unstandardized Coefficient**		**Standardized Coefficient**	**T**	**Sig.**
	B	Std. Error	B		
(Constant)	4.397	.734		5.993	.000
Companionship	-.268	.122	-.140	-2.189	0.30
Spirituality	.182	.087	.150	2.094	0.38
Rehabilitative Support	.435	.103	.275	4.236	.000
Regular Visitation	.375	.096	.283	3.925	.000

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Interpretation and discussion

It was shown in the table 4.4a above that the joint effect of independent variables on social support (companionship, spirituality, rehabilitative support and regular visitation) on palliative care process was significant R=.510; R^2= .260; Adj R_2 = .245; p< .05). The result in table 4.4b also shows that the joint effect of companionship, spirituality, rehabilitative support and regular visitation on palliative care was significant (F(4,197) = 17.295; R=.510 R^2 =. 260, Adj. R^2 = . 245; p< . 05). About 26.0% of the variation in palliative care process was accounted for by the independent variables while the remaining 74.0% was not due to chance (Null hypothesis was therefore rejected) : companionship (β= .140, P <.05); spirituality (β = .150, P <.05); rehabilitative support (β= .275, P<.05) and regular visitation (β= .238, P<.05).

The result above shows that the relative contribution of each of the four independent variables on palliative care of terminally-ill patients correlated significantly as follows: companionship (β= .140, P<.05); spirituality (β= .150, P<0.5); Rehabilitative Support (β= .275, P<.05) and Regular Visitation (β= .238, P<.05).

This agrees with Wills and Clark (1995) that social support is the perception and actuality that one is cared for, has assistance available from other people that make that individual part of a supportive network. These supportive resources can be emotional, informational and companionship in nature. Apart from this social support, health care has a complex effect on well-being, but it is calming and positive and changes one's assessment. Stressful event which would prevent the individual. (that is the terminally-ill in this study) from engaging in damaging behavioural responses (Taylor, 2011). The need for social support of patients with terminal illness remains pivotal for the palliative care practitioner, It is specifically concerned with the mental and emotional well-being of the patient and their family, including issues of self esteem and self efficacy. This is confirmed through an interview with one of the doctors that said:

> *"I perceive psychological and social support of the terminally-ill child as an irrevocable aspect of care for the innocent child that does not even understand the nitty gritty of the illness he/she is faced with, the only contact you have is either one of the child's parent or both of them. Effective communication is the key in which you must be ready to communicate correctly to the anxious parent of the sick child. In paediatric oncology, as soon as diagnosis is made, explicit explanation is rendered in*

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> *order to allow the parents of the child understand the pattern of care".*

From the findings, it could also be concluded that spirituality plays a major role in terminal illness. Macgans (1999) sees spirituality as religion and relationship with God which forms the basis of how an individual copes with illness and the management of the ailment, makes it important in the patients experience with terminal illness, the dying process and death. Bolen (1996) reported that Religion aids spiritual healing by supporting communities of faith, offering spiritual responses of the participants recorded a high percentages on spirituality as a key component of social support in terminal illness. In the same vein, Saunders (1967) described the characteristic of pain as loss of meaning, loss of hope, loss of identity due to lost roles and lack of independence, anger of God and a sense of betrayal for the patient nearing end of life, hence, the need to seek reconciliation and forgiveness from God. Spiritual healing can happen even when physical cure is not possible.

On the issue of companionship, a patient with terminal illness cannot care for himself alone, he needs help apart from health care team, the family caregiver who is a significant member of the patient's family has to be by the patient all the time, serve in the capacity of a helper who helps in decision-making for the patient at every stage of management. The multidisciplinary nature of palliative care requires that all the professional should periodically put heads together on how best the quality of life of the patient can be ensured.

In Kearney's (2000) submission, the potential for healing in the face of progressive disease is a potential rooted in the special relationship between the healer and the sufferer, this in itself is companionship between all those involved in the care of that terminally ill person, palliative care is not a stand alone phenomenon, but rather, a holistic type of care that all hands are on the deck to see to all aspects of care for the patient aimed at improving quality of life in the face of uncertainty. Morrow (2004), however, corroborated this in his assertion; described companionship in palliative care as a combination of the state of the art clinical competence with fidelity to the patient, ability to listen and to remain present in the face of much suffering and distress. Communication at a deeply personal level with the patient and family, palliative care involves having a genuine interest in the person as an individual and the ability to convey hope even in the face of death.

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Terminal illness diagnosis, as reflected in this study, can affect and limit the physical functioning for the patient. So rehabilitative support becomes an imperative measure to improve the quality of life for the patient as well as providing some comfort. In palliative care, patients are usually referred to the rehabilitative section of the health care facility to benefit from the various rehabilitative activities made available by the physiotherapists. Mueller (2001) supported this by confirming that there is health directorate on rehabilitative care and this also includes psychosocial rehabilitation, in its intervention, the rehabilitative plan helps to alleviate anxiety associated with the individual's perception of the physical incapacitation. In Okikiolu's opinion, a rehabilitation service provider includes general psychosocial counselling, adjustment/family/relationship counselling, parenting support, anger management, basic life skills training, and self help support group. This helps in maintaining effective social support for the terminally-ill and foster good relationship. Johnson (2001) argued that rehabilitative support/service during illness also incorporates teaching the patients skills that involve the use of their limbs to improve functioning. Such therapy includes knitting, sewing shoe, making, weaving baskets and the likes, being able to do some of this, serve as diversional therapy and improve their cognitive ability. The speech therapist also helps patients that suffer loss of speech from illness, in supporting the aspect of rehabilitation, the interview conducted with the physiotherapist revealed that:

> *"Terminal illness sometimes results in physical handicapping condition for the patient in which mobility becomes a problem, consult is usually brought to physiotherapy department, to help in rehabilitative care for the ill patient. So far, these patients are regarded as 'handle with care patients' because their care requires expertise, skill, and patience to be able to handle rehabilitative exercise for the ill patients, it is only if the patient is well relieved in other spheres of care that physiotherapy exercise can be included and I must say that the condition of the patient is what essentially determines the type of exercise you can do for him/her. Summarily for those that can withstand, some level of exercise, it helps them from being bed ridden and prevents pressure scores, some degree of mobility can be achieved".*

Similarly, the study revealed that social supports (companionship, spirituality, counselling) and regular visitations are parts of the supportive social network. Again, Wills and Clark (1995) stated that:

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> *Social supports such as companionship, regular visitation, cousellingetc have a complex effect on, but it is calming and positive, it may however change one's assessment of the stressful event or prevent the ill person from engaging in damaging behavioural responses (p.41)*

The above findings support the literature that these intervening variables are significantly related to social support network among terminally-ill patients receiving palliative care. This study carried out a correlation analysis of companionship, spirituality, rehabilitative support and regular visitation with the dependent variable as shown in table 4.4c

Table 4.4c Correlation matrix showing the relationship between social support (companionship spirituality, rehabilitative support and regular visitation on palliative care)

	Palliative Care Process	**Companionship**	**Spirituality**	**Rehabilitative Support**	**Regular Visitation**
Palliative Care Process	1				
Companionship	-.066	1			
Spirituality	.334**	.003	1		
Rehabilitative Support	.308**	.273**	.140**	1	
Regular Care Process	.410**	-.006	.515**	.176*	1
Mean	9.4554	2.5693	6.2723	5.6040	5.7673
SD	1.5868	0.8272	1.3045	1.0033	1.1971

To also complement the results of the multiple regression and the strength of contributions of the components of social support in palliative care process, the correlation matrix in the table 4.4c showed that all the social support components positively correlated with palliative care with overall mean of 9.45 and standard deviation. Their relative correlations of 1.58 with palliative care were as follows: Regular care (r=.410); spirituality (r= .334); rehabilitative support (r= .308) and companionship (r= -.066).

The findings of this study revealed that regular visitation as one of the social support variables has the highest significant relationship on palliative care of terminally ill patients with coefficient value of .410**. This supports some earlier study on the relevance of regular visitation in terminal conditions, as communication is very vital in this unpalatable health

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conditions. Sheldon (1999) found out that a greater percentage of patients would prefer to be informed of the diagnosis of their ailment. When this occurs, care may be in the hospital, hospice, palliative care centre, or the patient's home, whichever it is, the terminally-ill needs regular visitation. In this sensitive period of the ill patient's life, they begin to read meaning into the type of attitude displayed towards them both by family members and health care team.

At this same period spiritual support becomes key as well (value .334**) so the chaplain, religious groups, Imams or Rabbis play important role in the life of the dying by paying regular visits to them, spending time with them to know if there are discussions and unresolved or unfinished issues they would want resolved or settled before the inevitable happens. So the spiritualist's visit serves as channel of hope and solution to those areas of their lives that could make passing away more traumatic for them. Contrary to the insignificant value of companionship in this study, Heltz (2000) argued that in terminal illness, emotional support to spouses has been linked to significant decrease in early mortality, but the ill person needs to feel valued and accepted, maintain confidence, and self esteem, have their feelings known, be assured of being remembered and also participate in decision-making activities. The hospice, being a facility or serene environment for caring for terminally-ill persons is like a home away from home, though if not assessible, same can be done in the person's home, whereby the terminally ill can be visited regularly without restriction, so as to make the patient's final days be as meaningful and pleasant as possible.

4.5 Family integration and palliative care of the terminally-ill patients

The contributions of family integration components to the dependent measure as raised by objective four which states that, assess the relationship between the components of family integration (financial assistance, life style modification and re-allocation of roles) and palliative care of terminally ill patients. The results obtained were presented in table 4.5a, 4.5b and 4.5c which were obtained from the data collated on null hypothesis three ($H0_3$) which states that: *there is no significant relationship between each of the components of family integration and palliative care of terminally-ill patients* while detailed discussion follows:

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Table 4.5a Joint prediction of family integration (financial assistance, life style modification and re-allocation of roles) on palliative care process.

Model	Sum of squares	DF	Mean Square	F	Sig.
Regression	234.848	3	78.283	57.142	.000
Residual	271.251	198	1.370		
Total	506.099	201			

R = .681
R^2 = .464
Adj R^2 = .456

Table 4.5b: Relative effect of family integration (financial assistance, life style modification and re-allocation of roles) on palliative care process.

Model	Unstandardized coefficient		Standardized coefficient	T	Sig.
	B	Std. Error	β		
(constant)	6.724	.459		14.652	.000
financial assistance	.288	.028	.718	10.432	.000
life style modification re-	.197	.061	.172	3.203	.002
allocation roles	.223	.086	.176	-2.588	.010

Interpretation and discussion

Table 4.5a shows the joint prediction on the components of family integration (financial assistance, life style modification and re-allocation of roles) on palliative care as used for this study. It showed that the effect of the independent variables on family integration (financial assistance, life style modification and re-allocation of roles) on palliative care was significant at R= .681, R^2= .464, Adj R^2= .456.

It was shown also in the above table that the joint effect of financial assistance, life style modification and re-allocation of roles were significant (F(3,198) = 57.142; R= .681, R^2 = .464, Adj R^2= .456; P <.05). About 46.0% of the variation in palliative care process was accounted for by these variables. The results on table 4.4b above shows the relative contribution of each of the

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independent variable on the dependent: Financial Assistance (β = .718, P<.05); life style modification (β = .172, P<.05) and re-allocation of roles (β= .176, P<.05).

The result above shows that family integration components correlated significantly with palliative care of terminally-ill. This agrees with Olivere (1990) that no effective care can be carried out if the terminally-ill and the family are worrying about loss of income, he, therefore, warned that identifying financial needs is essential particularly with family care givers.

Smith (1998) argued that those who have a short time to live experience loss at every level of life. They, therefore, need financial assistance to cope. Sherman (2000), therefore, advocated various forms of assistance such as financial assistance, life style modification and re-allocation of roles as paramount. This is confirmed through an interview session with one of the family care givers:

> *Ever since my mother's illness started, I had to leave Lagos to come and assist in her care. I never knew what she described to me as a "lime sized boil" could result into her having a major operation done, she was counselled and I saw that she had a strong will and was quite positive that all would be well with her. I am really prepared to support and take care of her. When we got to the stage of her having to commence chemotherapy, we could afford four courses out of the eight courses that was prescribed for her. We then had to ask other significant family members for financial assistance which they responded within the limits of what they could afford. We are just trusting God for my mum's gratuity to be ready before we exhaust the funds we have presently*

It can, therefore, be deduced that whichever way one looks at it, the management of terminal conditions has financial commitment deep-rooted and since fingers are not equal, it usually gets to a point when financial assistance needs to be sorted, altered, family process also calls for reallocation of roles to be able to keep body and soul together. Again, sharing experience during an in-depth interview with a social worker, revealed that:

> *" My experience as social worker within the confines of these terminally-ill patients has been quite traumatic. This is because of the nature of their ailment in which they get to a point when they have financial constraints and usually they are referred to social workers for possible assistance. The fund available in Hospital Social Workers services is minimal compared to the*

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> *needs of these patients, but through discussions and interviews, with the patient/family we are able to meet their needs though in small measures. The units source for funds from Alanu foundation and well meaning individuals. The Social Workers even meet the patients family caregivers to discuss how best their financial problems can be addressed. In our department, we only give what the unit can afford which may not take care of all their needs but if funds are made available for patient's welfare this will go a long way to help them better".*

The study also discovered that those who are facing terminal illness in a family experience change in every realm of daily life relationship, role socialization and work patterns. The focus of the changes according to Parreant and Fothergill (2004) differs among family members. To this end, Olivere (1999), therefore, warned that the family must, especially, identify available health insurance through which the patient can benefit care.

On the issue of re-allocation of roles, the finding of this study reveals that the terminally-ill usually experience changes in all realms of daily life-relationships roles, socialization and work patterns. But the changes differ among family members, hence Hemtza (2003) argued that some family members easily become exhausted. Again, Martin, Barwich and Ryles (2008) attested to the above that there is the need for the re-allocation of roles because the terminally-ill patient changes in his/her relationships with everyone they knew. This could be as a result of the realization that the greatest change in their life (patients) is underway and that life as they know it would soon be gone.

This study, therefore, supports some earlier studies on financial assistance in the face of health challenges. Identifying financial needs is essential, particularly with family who have to deal with poverty, unemployment and poor housing. The medical social worker too can help source for funds from philanthropist organization or available health insurance scheme in that environment. Smith (1990) reported that those with short life expectancy face loss at every level, ranging from physical health independence career normal family life predictability, loss with its antecedent financial involvement which represent more than simply a crisis for the patient and significant others.

On life style modification, as one of the components of family integration in palliative care, this has to do with what used to be to what is now, the terminally-ill could be able to maintain their usual pattern for as long as their energy can carry them after which they begin to

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utilise feasible alternatives. Once they realised their capacities were changing, inability to adjust has ended up making them angry, frustrated and worthless. Mehtza and Ezer (2003) explained that when the situation gets to this stage, spouses take the patient's physical changes in stride, attributed the changes to the diseases and not the patient personally, and as a result, they are well able to empathise with their loved ones. 'Redefining', thus, comes into being, which is considering alternatives and recognising priorities as necessitated development (Andershed, 2004). In redefining, the ill person often accept spouses' offer of support and they are well able to talk about the changes that have occurred as a result of the illness. This would help them to accept re allocation of roles and cooperate with the care-giver.

Over the years, several researchers have examined various components in palliative care among which are chemical components in palliative care (Kuye and Soyanwo 2007), the major components highlighted that necessitated re-allocation of roles include pain, weakness and fatigue as major concerns of the terminally-ill. Hence, their life routine needs to be redefined since what they could do before is no longer possible, roles have to be reallocated Ferrel (2004) identified funding as a limited constraint among the terminally-ill. This has been largely contingent in the pursuit of regular analgesics, even in the developed country, a small cancer research funding is made available, making effective and adequate availability of relevant drugs. A problem for those that cannot afford, hence life style modification and allocation of roles and redefining become major decisions that should be brought to limelight' Onyeka (2003), however, reports in her own findings that there is need for global awareness of palliative care in the developing world, especially where such services are lacking. Travel cost for patients and relations to access care in health facility also results in additional financial pressure (Elumelu, Adempehin, Aikhomo and Amanor – Boadu 2013). Gender issues in palliative care (Akeredolu 2008) highlighted the role of women as wives and mothers in the home preventing them from presenting themselves early for medical attention.

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Table 4.5c Correlation matrix showing relationship between family integration (financial Assistance, life style modification and reallocation of roles) on palliative care

	Palliative Care Process	Diversional Support	Behavioural Support	Counselling Services	Emotional Support	Educational Counselling
Palliative Care Process	1					
Financial Assistance	.648**	1				
Life-style Modification	.316**	.245**	1			
Re-allocation of Roles	.316**	.641**	.181**	1		
Mean	9.4554	10.3861	5.0990	5.6931		
SD	1.5868	3.9524	1.3858	1.2518		

To complement the results of the multiple regression and the relative effect of the components of family integration on palliative care, the correlation matrix in the table 4.5c showed that there was significant relationship between the components of family integration and palliative care, their relative correlations with palliative care process were: financial assistance (r=.648), life style modification (r=.316) and reallocation of roles (r=.316).

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CHAPTER FIVE
SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

This chapter presents the summary, conclusion and recommendations based on the findings of this study. The educational implications, limitations and possible areas for further studies are also discussed in this chapter.

5.1 Summary

This study examined psychosocial supports and family integration as determinants of palliative care of the terminally-ill patients in the University College Hospital, Ibadan, Nigeria. To achieve this, the study was divided into five chapters. Chapter one dealt with the introduction with sub-headings such as: background to the study, statement of the problem, research objectives, research questions, significance of the study and scope of the study. The chapter ended with the operational definition of relevant terms.

Review of the related literature was extensively done in chapter two giving insight into previous studies as they are related to the present one. Empirical studies relevant to the study were also reviewed. In the same chapter, two theories were reviewed that provided theoretical framework. Upon appraisal of literature and formulated hypotheses, within which this study was hanged.

The third chapter of the study was on research methodology. This comprises of the research design, population, sample and sampling technique, research instruments, validity and reliability of the instruments, procedure for data administration and collection of data, a pattern of conduct of in-depth interview (IDI) as well as procedure of data analysis.

Chapter four of the study provided results of the findings and their discussions. The data collected were coded, analysed and presented with the use of descriptive and inferential statistical tools. The use of mean ($\bar{X}$) scores for the research questions and Pearson Product Moment Correlation and Multiple regression for the research hypotheses. The findings of this study revealed that:

Diversional support, behavioural supports, counselling services, emotional support and educational conselling were psychological factors that significantly correlated with palliative care for the terminally ill patients which was about 62% of the variation which was accounted for by the independent variables. The joint effect of the independent variables on psychological factors (diversional support, behavioural support, counselling services, emotional support and

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educational counselling) on palliative care was significant at 38.0% of the variation which was accounted for by the psychological independent variables.

- Psychological variables were significantly related to palliative care. Emotional support had the highest value with r= .686**, followed by educational counselling with r= .610**, next is diversional support with r= .538**, followed by behavioural support with r= .500** and counselling services with r= .451**.
- Companionship, spirituality, rehabilitative supports and regular visitations were social factors that significantly correlated with palliative care for the terminally ill patients which was about 26.0% of the variation which was accounted for by the independent variables. The joint effect of the independent variables (social factors) (companionship, spirituality, rehabilitative supports and regular visitations) on palliative care was significant at 74.0% of the variation which was accounted for by the social independent variables.
- Social variables were significantly related to palliative care. Regular visitations had the highest value with r= .410**, followed by spirituality with r= .334**, followed by rehabilitative supports with r= .308** and companionship with r= .066**
- Financial assistance, life-style modification, and re-allocation of roles were family integration factors that correlated significantly with palliative care which was about 54.0% of the variation accounted for by the independent variables. The joint effect of the independent variables-family integration (financial assistance, life-style modification, and re-allocation of roles) on palliative care was significant at 46.0% of the variation that was accounted for by the family integration variables.
- Family integration factors were significantly related to palliative care. Financial assistance had the highest value with r= .648**, followed by life-style modification with r= .316** and re-allocation of roles also with r= .316**
- The in-depth interview conducted among the selected health workers, social workers and the family care givers revealed that collaborations and supports among the earlier mentioned personalities enhanced palliative care services provided for the terminally ill patients. Also, since palliative care involves amalgamation of various roles and responsibilities. The interviews conducted revealed that these roles and responsibilities of the individuals and groups must be so coordinated to see to the less suffering and bring about hopes even is the face of uncertainties.

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5.2 Conclusion

The place of palliative care for terminally-ill patients cannot be overemphasised. The belief that the terminally-ill would or could close life at any stage of illness becomes the basis of anxiety on what the outcome of illness could be. A lot of previous researches have been conducted on the transition from curative care to palliative care in which they have little knowledge about the potentially complex situation. Evidence, thus, revealed that continuity of care and multidisciplinary collaboration are crucial to improving the experience of the patients. However, the sensitivity of the illness and possible outcome have been a major concern to the health care team and the sufferers.

5.3 Policy Implication of the study

There is the need to have a policy that will ensure that all persons with all forms of terminal or life limiting illnesses visit nearest health care facility, so as to make early diagnosis and selection of referral to appropriate hospital in order to assess comprehensive care.

Also, the psychosocial supports of the terminally ill should point towards solution for individual challenges in interacting with the management of the illness and the outcome.

Policies in palliative care practice should be periodically reviewed and be the standard of care right from when diagnosis is made, throughout the period of management irrespective of prognosis. Through this, psychological well-being of patients and family caregivers would be at equilibrium. Besides, in-service education on palliative care practice should be for all health workers in health institutions so that they would have an in-depth knowledge and function effectively in health centres for the effectiveness of the palliative care programme.

5.4 Recommendations

Premised on the findings, this study, therefore recommends that;

i. All health centres (Hospitals) should give priority attention to psychological factors determining palliative care for the terminally ills.

ii. Social factors such as companionship, spirituality, rehabilitative supports and regular visitations are key factors towards enhancing the capacity of the terminally ills. Efforts should be made to encourage these factors by all the care-givers

iii. Financial assistance, life-style modification and re-allocation of roles must be the concerns of the extended family members, philanthropists, and government agencies.

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All these are apt towards reducing the stress of the terminally ills and his/her family members. Health insurance schemes should function to care for the needy.

iv. The government should allocate more funds for the management of terminally-ill person. This would make them seek health care early and their financial constraints could be attended to. Medicines and investigations must be subsidized for the terminally-ills.

v. For effective palliative care for the terminally ill, the government should provide vehicles to ease transportation for those involved so that home based care can be rendered, those needing hospital admissions can be brought with the vehicles provided this would improve their psychological well-being and families would be comforted even if the inevitable happens

5.5 Contributions to knowledge

This work has brought to limelight the issue of palliative care and its relevance in the plight of those with terminal-illness. It has highlighted the importance of quality of life and the need to see both the patient and family as a unit of care because whatever happens to this patient would inadvertently affect the family members;

The study had been able to establish the fact that effective palliative care prolongs the life of patient who is expected to have died within a short period of time; the study had identified that early presentation of terminal-ill patients prolongs their life because when diagnosis is made, early high possibility of reduction of spread of the illness is possible.

The need for financial assistance has been discovered as key in crucial to for the terminally ill, hence life style modification, reallocation of roles, rehabilitative support with financial support are essential factors in good delivery of palliative care process.

Finally, counselling services, emotional support and spirituality supports are sensitive factors to be given consideration even in the face of uncertainty by all including the health workers, social workers and the family care-givers.

5.6 Limitations to the study

The study covered terminally ill patients in seven selected wards and four outpatient clinics in University College Hospital. Financial constraint on the part of the researcher made it impossible for all the terminally-ill patients in all the wards to be included in the study. The nature of this study would, however, not allow this to happen because the unconscious

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terminally-ill patients could not be included in the study. The diagnosis of the terminally-ill patients used for this study were limited to those with cardiac problems, end stage kidney diseases, neurological problems, cancer and HIV. The study would have been more extensive if all terminally ill conditions present in the hospital were used, but time and finances could not make this possible.

There was also the issue of ethical approval from UI/UCH ethical committee, which took a long time as the proposal of this research protocol required a lot of scrutiny and corrections before ethical approval was obtained. Even after being granted the ethical approval, the researcher had to seek permission from the chairman medical advisory committee of the hospital for approval to distribute copies of the questionnaire on the wards, while letters had to be written to the various heads of unit for approval before questionnaires were distributed within the neurological wards and clinics. There was administrative bottle neck in which one of the heads of unit prevented the researcher from distributing questionnaires among the patients, giving reason that their diagnosis were personal to them and their carers. So, questionnaires were not allowed. Other relevant wards were used instead.

However, regardless of the problems identified, the findings of the study are reliable and sustainable empirically to be generalised for all the wards and clinics of the tertiary health institutions within which the study was carried out.

5.7 Suggestion for further studies

Sequel to the limitations of this study, the researcher wishes to state that other researches could be carried out further in other comprehensive health facilities offering palliative care, and also, a comparative study can be carried out on palliative care of patients with terminally illness in Federal medical health institutions and those receiving care in the traditional-based homes.

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QUESTIONNAIRE FOR HEALTH WORKERS

Dear Respondents

The attached questionnaire is basically to elicit information on Health Worker's perception on of Palliative care services of terminally-ill patients in University College Hospital, Ibadan. It is primarily for research purpose. All your responses will be treated with utmost confidentiality.

Your cooperation is highly appreciated.

Thanks.

SECTION A: HEALTH WORKERS' SOCIO DEMOGRAPHIC DATA

Please tick as appropriate

Age:
10-20 [ ]
21-30 [ ]
31-40 [ ]
41-50 [ ]
50 & above [ ]

Sex:
Male [ ]
Female [ ]

Marital Status:
Single [ ]
Married [ ]
Divorced [ ]
Widowed [ ]
Separated [ ]

Religion:
Christian [ ]
Muslim [ ]
Others [ ]

Occupation/Profession ____________________

If professional, Area of Specialty _______________

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SECTION B: PALLIATIVE CARE SERVICES QUESTIONNAIRE

Please tick as appropriate: Strongly agree (SA) Agree (A) Disagree (D) Strongly disagree (SD)

S/N		**SA**	**A**	**D**	**SD**
1	Palliative care should be the standard medical treatment for patients who are suffering from a terminal illness.				
2	Patients should have the right to determine their own degree of medical intervention.				
3	Pain at the end of life is an inevitable part of the dying process.				
4	Pain medication should be given as needed to terminally-ill patients.				
5	Addiction to oral morphine is not a serious issue given that terminally ill patients have a short time to live.				
6	Estimation of pain by a Health worker is a more valid measure of pain than patient self-report.				
7	Complete pain relief is a reasonable goal even when the pain is not caused by a terminal condition.				
8	A patient should experience discomfort prior to receiving the next dose of pain medications.				
9	Patients should be maintained in a pain free state.				
10	Patients have the right to determine their own degree of psychosocial intervention.				
11	The most appropriate person to make end of life decisions is the patient's primary care provider.				
12	I do not like talking about death and dying with patients.				
13	As a rule, terminally-ill patients prefer not to talk about death and dying.				
14	Spiritual care should include counselling the terminally ill patients.				
15	Opening discussions of end of life care should be deferred until there is no further effective curative treatment available.				

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FACULTY OF EDUCATION
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QUESTIONNAIRE FOR PATIENTS

Dear Respondents

The attached questionnaire is basically to elicit information on palliative care services of the terminally-ill at the University College Hospital, Ibadan. It is primarily for research purpose. All your responses will be treated with utmost confidentiality.

Your cooperation is highly appreciated.

Thanks.

SECTION A: PATIENT'S SOCIO DEMOGRAPHIC DATA

Please tick as appropriate

Age:
10-20 [ ]
21-30 [ ]
31-40 [ ]
41-50 [ ]
50 & above [ ]

Sex:
Male [ ]
Female [ ]

Marital Status:
Single [ ]
Married [ ]
Divorced [ ]
Widowed [ ]
Separated [ ]

Religion:
Christian [ ]
Muslim [ ]
Others [ ]

Occupation/Profession ____________________

Period of illness ___________________________

SECTION B: PSYCHO-SOCIAL SUPPORT QUESTIONNAIRE

Instruction: For each of the following statements, kindly tick (√) the best appropriate. SA (Strongly Agree); A (Agree); D (Disagree); SD (Strongly Disagree).

S/N	ITEMS	SA	A	D	SD
1.	There is a special person who is around when I am in need.				
2.	There is a special person with whom I can share my joys and sorrows.				
3.	My family really tries to help me.				
4.	I get the emotional help and support I need from my family.				
5.	I have a special person who is a real source of comfort to me.				
6.	My friends really try to help me.				
7.	I can count on my friends when things go wrong.				
8.	I can talk about my problems with my family.				
9.	I have friends with whom I can share my joys and sorrows.				
10.	There is a special person in my life who cares about my feelings.				
11.	My family is willing to help me make decisions.				
12.	I can talk about my problems with my friends.				
13.	I have support in what I do.				
14.	I have understanding of my present condition.				
15.	I have information that helps me overcome my difficulties.				
16.	I can face up to my problems.				
17.	I have financial problems.				
18.	I feel I am a burden to my friends.				
19.	I am happy about my relationship with other family members.				
20.	I find peace in my place of worship.				

UNIVERSITY OF IBADAN

FACULTY OF EDUCATION
UNIVERSITY OF IBADAN, IBADAN
QUESTIONNAIRE FOR FAMILY CARE GIVERS

Dear Respondents

The attached questionnaire is basically to elicit information from family caregivers involved in care of the terminally-ill patients receiving palliative care at University College Hospital, Ibadan. It is primarily for research purpose. All your responses will be treated with utmost confidentiality.

Your cooperation is highly appreciated.

Thanks.

SECTION A: FAMILY CAREGIVERS SOCIO DEMOGRAPHIC DATA

Please tick as appropriate

Age:
10-20 [ ]
21-30 [ ]
31-40 [ ]
41-50 [ ]
50 & above [ ]

Sex:
Male [ ]
Female [ ]

Marital Status:
Single [ ]
Married [ ]
Divorced [ ]
Widowed [ ]
Separated [ ]

Religion:
Christian [ ]
Muslim [ ]
Others [ ]

Occupation/Profession ________________________

Period of patients illness ___________________________

Relationship to patient ____________________________

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SECTION B: FAMILY SUPPORT QUESTIONNAIRE

Please tick (√) the appropriate answer Strongly Agree (SA), Agree (A), Disagree (D), Strongly Disagree (SD).

S/N	ITEM	SA	A	D	SD
In the course of caring for him/her:					
1	I have sleep pattern disturbance.				
2	Caring for him/her has been convenient for me.				
3	Caring for him/her is restrictive.				
4	His/her ailment has created alteration in the family's role performance.				
5	Caring for him/her has altered my personal plans.				
6	His/her ailment has caused some emotional disturbance.				
7	He/she exhibits altered behavioural pattern.				
8	His/her illness has caused financial constraint.				
9	Other family members have dumped his/her care to me.				
10	My financial resources are adequate to pay hospital bill.				
11	I get easily tired as a result of caring for him/her.				
12	His/her illness has caused me a feeling of resentment.				
13	I am really prepared to take care of him/her.				
14	I have heard of palliative care before.				
15	Palliative care is meant for those nearing end of life.				
16	The care positively influence his/her well-being.				
17	I prefer to care for my patient at home.				
18	I prefer to care for him/her in the hospital.				

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ILÉ ÌWÉ TI YUNIFÁSÍTÌ
Ẹ̀KA TÍ AKẸ́KỌ ÀWỌN OLÙKỌ́NI
ÌBÉRÈ FÚN ÀWỌN ÒṢÌṢẸ́ ÌWÒSÀN

Sí àwọn Olùdáhùn

Ìbéré tí ó wà nínú ìwé yii wà fún àti ọ̀rọ̀ lórí ìmọ̀ lórí ìtọ́jú tí ó wà fún àwọn aláìsàn tí ń gba ìtọ́jú lórí àìsàn tí ó dín ìrora ikú ní ilé-Ìwòsàn Orita mẹ́fà tí a mọ̀ní Yunifásítì Kọ́lẹ́jì Họspitítù, Ìbàdàn. Ìbéré yii wà fún iwadi nìkan. Gbogtbo ìdáhùn rẹ kòní hàn sí ẹlòmíràn. Mo dúpẹ̀ fún ìfọwọ́sọwọ́ pọ̀ rẹ.

Ipele tàbí ìsọ̀rí Kíní

Ìbérè lórí ohun tó jẹ́ mọ́ mi

Ọjọ́ orí

10 – 20	[ ]	ọdún mẹwa sí ogun ọdún
21 – 30	[ ]	ọdún mọ́kànlélógún sí ọgbọ̀n ọdún
31 - 40	[ ]	ọdún mọ́kànlélọ́gbọ̀n sí ogójì ọdún
41 - 50	[ ]	ọdún mọ́kànlèlógójì sì àdọ́ta ọdún
50 +	[ ]	Àdọ́ta ọdún lọ so òkè

Ìbérè lórí Ẹbí

Mi o ti lọ́ọ̀kọ̀ tàbí gbéyàwó [ ]
Mo ti lọ́ọkọ̀ tàbí gbéyàwó [ ]
Mo ti kọ lọ́kọ tàbí ìyàwó mi silẹ [ ]
Opó ni míi [ ]
Èmi àti ìyàwó mi tàbí ọkọ ti yaapa [ ]

Ìbérè lórí Ẹ̀sìn

Onígbàgbọ́ ni mí [ ]
Mùsùlùmí ni mí [ ]
Àwọn ẹ̀sìn míràn [ ]

Iṣẹ́ tí mo ń ṣe:……………………………………………

Pàtàkì iṣẹ́ tí mo ńṣe:……………………………………

Ìsọ̀rí Kejì

Jọ́wọ́ mú ọ̀kan tí ó bá ṣe pàtàkì jùlọ nínú àwọn ìbẹ́rè yíi.

		Mo fara mọ́ mọ	**Mo fara mọ́**	**Mí ò fara mọ**	**Mí ò fara mọ rara**
1.	Ọ̀nà láti dín ìnira aláìsan tí ń jẹ́ ìrora kù nítorí àìsàn tí ó le já sí ikú ni ọ gbọdọ̀ ṣe pàtàkì jùlọ				
2.	Aláìsàn ní àṣẹ láti sọ irú ìtọju tó bá wu láti gbà				
3.	Ìrora àti ìnira jẹ́ àpẹẹrẹ pé ikú tí ń bọ̀ ní ìgbàtí ènìyàn bá wà ní akete àìsàn.				
4.	Ẹni tí ó wà nínú ìnira àti ìrora gbọ́dọ̀ ma gba òògùn tí yíò dí ìnira kù nígbàkúgbà				
5.	Aìmále má lo ògùn ara ríro fún ẹni tí ó wà nínú àìsàn tó le já sí ikú ki iṣe àìsan tó búru jọjọ				
6.	Ìdiwọ̀n ìrora aláìsàn, bí òṣìṣẹ́ ìwòsàn bá ṣ eṣe ìdiwọ̀n ìrora aláìsàn ṣe pàtàkì ju bí aláìsàn fún rarẹ̀ báṣe júwe ìrora náà.				
7.	Ohun tó ṣe pàtàkì ni láti dá ìrora dúró ní ìdubúlẹ̀ àìsàn iba sepé àìsàn ohun kò le gba ẹ̀mí.				
8.	Aláìsàn gbọ́dọ̀ wà nínú àìnira tàbí irora kó tó gba ògùn tí ó dín ìrora kù.				
9.	Aláìsàn gbọ́dọ̀ wà ní ipò àìnira nígbàgbogbo				
10.	Aláìsàn ní àṣẹ láti sọ nípa ohun tó le bá lọ́kàn jẹ́ àti láti wá ìdáhùn síi.				
11.	Ẹni àkọ́kọ́ tí ó ń tọ́jú aláìsàn ni ó le pàṣẹ nípa àpẹẹrẹ òpin ayé aláìsàn tí ó bá di wípé ó ń dé ojú ikú.				
12.	Mí ò kìí fẹ́ má sọ nípa ikú pṣlú aláìsàn.				
13.	Gẹ́gẹ́ bí òfin àwọn aláìsàn tí ó wà nínú àìsàn tí kìí (ko) gbògùn kìí fẹ́ sọ nípa ikú.				
14.	Kámá sọ̀rọ̀ nipa ẹ̀sìn àti ìgbàgbọ́ yẹ kó wà nínú ìtọ́jú fún aláìsàn tí ó wà nínú ìrora àìsàn tí kò gbógùn.				
15.	Ọ̀rọ̀ nípa ìgbẹ̀hìn ayé tàbí ikú gbọ́dọ̀ di ìgbà tí kò básí ọ̀nà àbáyọ fún ìtọ́jú àìsàn mọ				

ẸKA TÍ AKẸ́KỌ ÀWỌN OLÙKỌ́NI
ILÉ ÌWÉ ẸKỌ́ GÍGA TI YUNIFÁSÍTÌ
ILÚ-ÌBÀDÀN
ÌBÉRÈ FÚN ÀWỌN TÍ Ó N GBA ÌTỌ́JÚ NÍ ILÉ ÌWÒSÀN

Sí àwọn Olùdáhùn Ìbérè

Ìwé ìbérè yíi wà fún láti wadi ọ̀rọ̀ lẹ́nu yín lórí ìtọ́jú fún àwọn ènìyàn tí ń ṣe àìsàn tí kìí gba òògùn bọ̀rọ̀ ní ilé Ìwòsàn ti ìjọba, ilé ẹ̀kọ́ gíga tíi Orítamẹ́fà tí a mọ̀ síi Yunifásítì Kọ́lẹ́jì Hosibítù Ìbàdàn.

Ìbérè yí wà fún ìwadi nìkan. Gbogbo ìdáhùn yín kò ní hàn sí ẹnikankan. Ìfọwọ́sọwọ́pọ̀ yín sì ṣe pàtàkì

Ẹ sé o.

Ipele Kíní

Ohun tó jẹ́ mọ́ọ mi

Lí àná láti dáhùn ìberè

Mú ọ̀kan nínú àwọn ìberè yíi.

Ọjọ́ orí

10 – 20	[ ]	ọdún mẹwa sí ogun ọdún
21 – 30	[ ]	ọdún mọ́kànlélógún sí ọgbọ̀n ọdún
31 - 40	[ ]	ọdún mọ́kànlélọ́gbọ̀n sí ogóji ọdún
41 - 50	[ ]	ọdún mọ́kànlèlógóji sì àdọ́ta ọdún
50 +	[ ]	Àdọ́ta ọdún lọ so òkè

Ẹ̀yà tí mojẹ́

Ọkùnrin

Obìnrin

Iṣẹ́ tí mo ń ṣe:…………………………………………………

Pàtàkì iṣẹ́ tí mo ńṣe:…………………………………………

UN

Ìpele Kejì

Ìlànà láti dáhùn ìberè

Mú èyí tí ó bá yẹ nínú àwọn ìberè yìí

		Mo fara mọ́ mọ	Mo fara mọ́ díẹ̀	Mí ò fara mọ	Mí ò fara mọ rara
1.	Ènìyàn pàtàkì kan ma ń wá ní tòsí nígbàkúgbà tí mo bá nílò ìrànlọ́wọ́.				
2.	Ènìyàn pàtàkì kan wá tí ó le bá mi pín nínú ìdùnú àti ìbànújẹ́ mi,				
3.	Àwọn ẹbí mi n'gbìyànjú láti ràn mí lọ́wọ́.				
4.	Mo má ń n'rí ìmí-ẹ̀dùn pẹ̀lú àtìlẹ́hìn tí mo ní lò láti ọ̀dọ̀ àwọn ẹbí mi.				
5.	Mo ní ènìyàn pàtàkì kan tí ó jẹ́ alátìlẹ́hìn fún mi.				
6.	Àwọn ọ̀rẹ́ mi ma nràǹmílọ́wọ́.				
7.	Mo ní ìgbẹ́kẹ̀lé nínú àwọn ọ̀rẹ́ mi tí ohunkóhun bá yẹ gẹ̀rẹ̀ fún mi.				
8.	Mo le báa àwọn ẹbí mi sọ nípa ìsoro mi.				
9.	Mo ní àwọn ọ̀rẹ́ tí ó le dúró tí mi nígbà adún àti ìkorò.				
10.	Mo ní ènìyàn pàtàkì tí ó ń ṣe àfẹ́rí mi nípa ìfọ̀kànbalẹ́ mi.				
11.	Àwọn ẹbí mi ma ń ràn mí lọ́wọ́ láti ṣe ìpinnu nípa ìtọ́jú mi.				
12.	Mo lè sọ fún àwọn ọ̀rẹ́ mi nípa ìsòro mi.				
13.	Mo ní àtílẹ́hìn nínú ohun tí mo ń ṣe.				
14.	Mo ní ìmọ̀ nípa ohun tí mo ń ṣe ní lọ́wọ́lọ́wọ́ yi.				
15.	Mo ní àǹfààni ìmọ̀ tí o ránmílọ́wọ́ láti borí àwọn ìsòro mi.				
16.	Mo lè dojú kọ ìsòro mi,				
17.	Mo ní wàhálà owó.				
18.	Mo mọ̀ pé mo jẹ́ wàhálà fún àwọn ọ̀rẹ́ mi.				
19.	Inú mí dùn sí aṣepọ̀ èmi àti àwọn ẹbí mi.				
20.	Mò ń rí àlàfíà ní ilé ìjọ́sìn mi.				

ILÉ ÌWÉ YUNIFÁSÍTÌ TI ILÚ-ÌBÀDÀN
ẸKA TÍ AKẸ́KỌ ÀWỌN OLÙKỌ́NI
ÌBÉRÈ FÚN ÀWỌN ẸBÍ TÍ Ó NTỌ́JÚ ÀWỌN ALÁÌSÀN

Sí àwọn

Ìbéré tí ó wà nínú ìwé yìí wà fún àti wadi ọ̀rọ̀ ómọ̀ lóri ìtọ́jú tí ó wà fún wọn.

Ipele tàbí ìsọ̀rí kíní

Ohun tó jẹ́ mọ́ mi mú ọ̀kan nínú àwọn ìbéré yìí

Ọjọ́ orí

10 – 20 [ ] ọdún mẹwa sí ogun ọdún

21 – 30 [ ] ọdún mọ́kànlélógún sí ọgbọ̀n ọdún

31 - 40 [ ] ọdún mọ́kànlélọ́gbọ̀n sí ogójì ọdún

41 - 50 [ ] ọdún mọ́kànlèlógójì sì àdọ́ta ọdún

50 + [ ] Àdọ́ta ọdún lọ so òkè

Ẹyà tí mojẹ́

Ọkùnrin

Obìnrin

Ẹ̀sìn wo ni mo ń ṣe?

Onígbàgbọ́ [ ] Mùsùlùmí [ ]

Ẹ̀sin Àbáláyé

Àsìkò wo ni àìsàn yìí bẹ̀rẹ̀?

Iṣẹ́ tí mo ń ṣe:………………………………………………

Ìsọ̀rí Kejì

Mú ìdáhùn tó ṣe pàtàkì nínú àwọn ìbérè yíí.

	. Ní àsìkò tí mò ń tọ́jú ẹni tí ó ń ṣe àìsàn	Mo fara mọ́ mọ	Mo fara mọ́	Mí ò fara mọ
1.	Èmi kò rí orun sún rárá,			
2.	Ìtọ́jú ẹnití ó ń ṣe àìsàn yí kò rọrùn fún mi rárá.			
3.	Bí mo ṣe ń tọ́jú rẹ̀ kì jẹ́kì ń le ṣe ǹkan míràn,			
4.	Àìsàn rẹ́ ti di àwọn ǹkan míràn lọ́wọ́ mi nínú ẹbí.			
5.	Bí mo ti ń tọ́jú rẹ̀ ń dí àwọn àtiṣe ǹkan ara mi lọ́wọ́,			
6.	Àìsàn rẹ̀ ń dá ẹ̀dùn ọkàn sí ara mi.			
7.	Àìsàn rẹ̀ tí ṣe okùnfà àwọn ìwà tí kò ṣe déédé.			
8.	Àìsàn rẹ̀ ti jẹ́ kí owó dín kù lọ́wọ́ mi.			
9.	Àwọn ẹbí tókù kò bá mi dásí ìtọ́jù àìsàn èniyàn wa yi.			
10.	Owó ọwọ́ wà kó fún mi láti san owó ilé ìwòsàn			
11.	Ó tètè máa ń rẹ̀ mí nítorí bí mo ṣe má ń tọ́jú rẹ̀.			
12.	Mo ní ọkàn àìbíkátà sí ẹbí mi aláìsàn yi.			
13.	Mo fẹ́ láti tọ́jú aláìsàn mi.			
14.	Mo ti gbọ́ nípa àìsàn tí kò gbó ìtọ́jú bọ̀rọ̀ ri.			
15.	Ìtọ́jú rẹ̀ yá mi lára láti ṣe,			

UNI

SUB THEMES OF IDI

1. Perception of health Workers, Terminally-ill patients and family care givers on palliative care
2. Psychological support and palliative care
3. Family integration and palliative care
4. Social Support and palliative care

IN-DEPTH INTERVIEW GUIDE

Patient:

Greetings:

Please will like to ask some questions relating to your health and the care you receive in this hospital.

1. How long have you been on admission/have been coming to this clinic?
2. Are you comfortable with the care you receive here?
3. Do you consider palliative care appropriate to your present condition and what is your own perception on this palliative care?

Family Care giver:

1. Please can you share your experience on palliative care that your relation has been receiving in this hospital?
2. In your own opinion, are you comfortable with this type of care for him/her?
3. Are you able to cope financially with the demand of his/her management?

Health Worker:

1. How do you perceive palliative care?
2. Why do you think it is appropriate for end of life care?
3. Can you please tell me your experience on these patients receiving palliative care and their family care givers?

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INFORMED CONSENT FORM

UI/UCH EC Number:	**UI/EC/12/0236**
TITLE OF RESEARCH:	**Psychosocial Support and Family Integration as Determinants of Palliative Care of Terminally-ill Patients in University College Hospital, Ibadan.**

Dear Respondent,

I am a postgraduate student from the Department of Adult Education in University of Ibadan. I am conducting research on the above title.

The attached questionnaires are strictly for research purpose, kindly answer and tick as appropriate. Confidentiality is strictly ensured.

How long will I be in this study?

You will be in the study only for the length of time to complete the questionnaire, but this is completely voluntary

What are the risks of the study.

There are no anticipated physical risks as a result of participating in this study

Are there any benefits to taking part in the study.

Participating in this study would provide opportunity to create awareness that would make individuals and group assess the benefits provided in health care to improve the quality of life of those with terminal illness.

What other options are available?

Your participation in this study is voluntary. You may stop participating anytime, though you may choose not to participate at all.

What are the costs?

There is no cost attached

What about confidentiality?

The data collected are strictly for research purpose and information gathered will be treated with utmost confidentiality. Consent would be kept for at least five years. No name or identifying information would be used for this study.

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Who do I call if I have questions or problems?

If you have further questions about the study, you may call the researcher (08033567270 or Dr. F.A. Okanlewon (08055071838) and Prof. Deborah Egunyomi (08068052153)

CONTACTS

You have been given the telephone numbers of the study personelle conducting this study. You can call them anytime in the course of carrying out this study.

RESPONDENT,

The research project has been explained to me, the process has been identified and I will be given a signed copy of this consent form for my records.

I agree to participate in this study. My participation is voluntary and I do not have to sign this form if I do not want to be part of this study.

Signature of Respondent__________________________
Date:____

PERSON OBTAINING CONSENT

I have explained to __________________ the nature and purpose of the study and the risks involved. I have answered and will answer all questions to the best of my ability. The signed copy of the consent will be given to the respondent.

Signature of Person Obtaining Consent _________________ Date________________

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(A) The Terminally-ills:

S/N	Psycho-Social Support	SD	D	A	SA	Mean	S.D
1	There is a special person who is around when I am in need	2 1.0%	16 7.9%	85 42.1%	99 49.0%	3.39	.68
2	There is a special person, with whom i can share my joys and sorrows.	1 1.5%	16 7.9%	96 47.5%	89 44.1%	3.35	.65
3	My family really tries to help me.	2 1.0%	7 3.5%	112 55.4%	81 40.1%	3.35	.60
4	I find peace in my place of worship.	9 4.5%	11 5.4%	87 43.1%	95 47.0%	3.33	.77
5	I get the emotional help and support I need from my family.	2 1.0%	11 5.4%	120 59.4%	69 34.2%	3.27	.60
6	I can talk about my problems with my family.	4 2.0%	12 5.9%	115 56.9%	71 35.1%	3.25	.65
7	I have a special person who is a real source of comfort to me.	3 1.5%	21 10.4%	103 51.0%	75 37.1%	3.24	.69
8	There is a special person who is a real source of comfort to me.	5. 2.5%	15 7.4%	108 53.5%	74 36.6%	3.24	.70
9	I have support in what I do.	7 3.5%	16 7.9%	127 62.9%	52 25.7%	3.11	.68
10	I am happy about my relationship with other family members.	11 5.4%	24 11.9%	111 55.0%	56 27.7%	3.05	.78
11	My family is willing to help me make decisions.	8 4.0%	24 11.9%	127 62.9%	43 21.3%	3.01	.70
12	I have understanding of my present condition.	9 4.5%	42 20.8%	102 50.5%	49 21.3%	2.95	.70
13	I have information that helps me overcome my difficulties.	12 5.9%	54 26.7%	109 54.0%	27 13.4%	2.75	.76
14	I can face my problems.	10 5.0%	74 36.6%	93 46.0%	25 12.4%	2.66	.76
15	I have friends with whom I can share my joy and sorrow.	19 9.4%	73 36.1%	86 42.6%	24 11.4%	2.57	.82
16	I have financial problems.	21 10.4%	68 33.7%	90 44.6%	23 11.4%	2.57	.83
17	I can talk about my problems with my friends.	17 8.4%	74 36.6%	95 47.0%	16 7.9%	2.54	.76
18	My friends really try to help me.	17 8.4%	77 38.1%	92 45.5%	16 7.9%	2.53	.76
19	I can count on my friends when things go wrong.	17 8.4%	95 47.0%	72 35.6%	18 8.9%	2.45	.77
20	I feel I am a burden to my friends.	37 18.3%	77 38.1%	71 35.1%	17 8.4%	2.34	.87

Weighted $\bar{x}$ = 3.14

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(B) The Family Caregivers:

The perceptions of family caregivers on palliative care of terminally-ill patients as raised by objective 5 which examined the perceptions of the family caregivers on the palliative care.

Table 4.1b: Mean scores of the perceptions of the family caregivers on palliative care of the terminally ill patients

S/N	Family Support	SD	D	A	SA	Mean	S.D
1	His/Her ailment has caused some emotional disturbance.	3 1.5%	30 14.9%	114 56.4%	55 27.2%	3.09	.69
2	Caring for Him/Her has altered my personal plans.	7 3.5%	36 17.8%	93 46.0%	66 32.7%	3.08	.80
3	His/Her ailments has created alteration in the family's role performance.	16 7.9%	38 18.8%	77 38.1%	71 35.1%	3.00	.93
4	The care positively influences His/Her well-being.	15 7.9%	23 11.4%	119 58.9%	45 22.3%	2.96	.80
5	I am really prepared to take care of Him/Her.	10 5.0%	32 15.8%	118 58.4%	42 20.8%	2.95	.75
6	His/Her Illness has caused financial constraints.	4 2.0%	54 26.7%	95 47.0%	49 24.3%	2.94	.77
7	I prefer to care for Him/Her in the hospital.	25 12.4%	47 23.3	55 27.2%	75 37.15	2.89	1.05
8	Caring for Him/Her is restrictive.	20 9.9%	56 27.7%	90 44.6%	36 17.8%	2.70	.88
9	I have sleep pattern disturbance.	34 16.8%	55 27.2%	81 40.1%	32 15.8%	2.55	.95
10	He/She exhibits altered behavioural pattern.	23 11.4%	78 38.6%	75 37.1%	26 12.9%	2.51	.86
11	I have heard of palliative care before.	37 18.3%	63 31.2%	73 36.1%	29 14.4%	2.47	.95
12	I get easily tired as a result of caring for Him/Her.	21 10.4%	84 41.6%	82 40.6%	15 7.4%	2.45	0.78
13	Caring for Him/Her has been convenient.	29 14.4%	87 43.1%	73 36.1%	13 6.4%	2.35	.80
14	His/Her illness has caused me a feeling of resentment.	26 12.9%	91 45.0%	73 36.1%	12 5.9%	2.35	.78
15	Palliative care is meant for those nearing end of life.	52 25.7%	63 31.2%	56 27.7%	31 15.3%	2.33	1.02
16	I prefer to care for my patient at home.	55 27.2%	67 33.2%	55 27.2%	25 12.4%	2.25	.99
17	Other family members have dumped His/Her care to me.	43 21.3%	84 41.6%	62 30.7%	13 6.4%	2.22	.86
18	My financial resources are adequate to pay hospital bill.	36 17.8%	107 53.0%	47 23.3%	12 5.9%	2.17	.79

Weighted $\overline{x}$ = 3.10

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(C) The Health Workers:

The perception of health workers on the palliative care as raised by research objective 5 of the study which examined the perception of the health workers on palliative care of the terminally-ill.

Table 4.1c: Mean scores of the perception of Health workers on the palliative care for the terminally-ill patients.

S/N	Palliative Care Services	SD	D	A	SA	Mean	S.D
1	Palliative care should be the standard medical treatment for patients who are suffering from a terminal illness.	1 .5%	6 3.0%	64 31.7%	131 64.9%	3.61	.58
2	Pain medication should be given as needed to terminally-ill patients.	3 1.5%	4 2.0%	73 36.1%	122 60.4%	3.55	.63
3	Spiritual care should include counselling the terminally-ill patients.	4 2.0%	15 7.4%	91 45.0%	92 45.5%	3.32	.70
4	Patients should be maintained in a pain free state.	13 6.4%	13 6.4%	87 43.1%	89 44.1%	3.25	.83
5	Patients should have the right to determine their own degree of medical intervention.	6 3.0%	29 14.4%	100 49.5%	67 33.2%	3.13	.75
6	Patients have the right to determine their own degree of psychosocial intervention.	6 3.0%	30 14.9%	95 47.0%	71 35.1%	3.13	.77
7	Complete pain relief is a reasonable goal even when the pain is not caused by a terminal condition.	12 5.9%	29 14.4%	103 51.0%	58 28.7%	3.01	.80
8	Addiction to oral morphine is not a serious issue given that terminally-ill patients have a short time to live.	17 8.4%	45 22.3%	94 46.5%	46 22.8%	2.81	.87
9	Opening discussions of end of life care should be deferred until there is no further effective curative treatment available.	31 15.3%	58. 28.7%	66 32.7%	47 23.3%	2.61	1.00
10	Pain at the end of life is an inevitable part of the dying process.	44 21.8%	61 30.2%	65 32.2%	32 15.8%	2.42	.99
11	As a rule, terminally-ill patients prefer not to talk about death and dying.	34 16.8%	91 45.0%	66 32.7%	11 5.4%	2.28	.80
12	I do not like talking about death and dying with patients.	41 20.3%	82 40.6%	65 32.2%	14 6.9	2.27	.86
13	The most appropriate person to make end of life decisions is the patient's primary care provider.	44 21.8%	83 41.1%	55 27.2%	20 9.9%	2.25	.90
14	Estimation of pain by a Health worker is a more valid measure of pain than patient's self report.	57 28.2%	101 50.0%	33 16.3%	11 5.45	2.01	.83
15	A patient should experience discomfort prior to receiving the next dose of pain medication.	72 35.6%	85 42.1%	31 15.3%	14 6.9%	1.92	.87

Weighted $\bar{x}$ = 3.21

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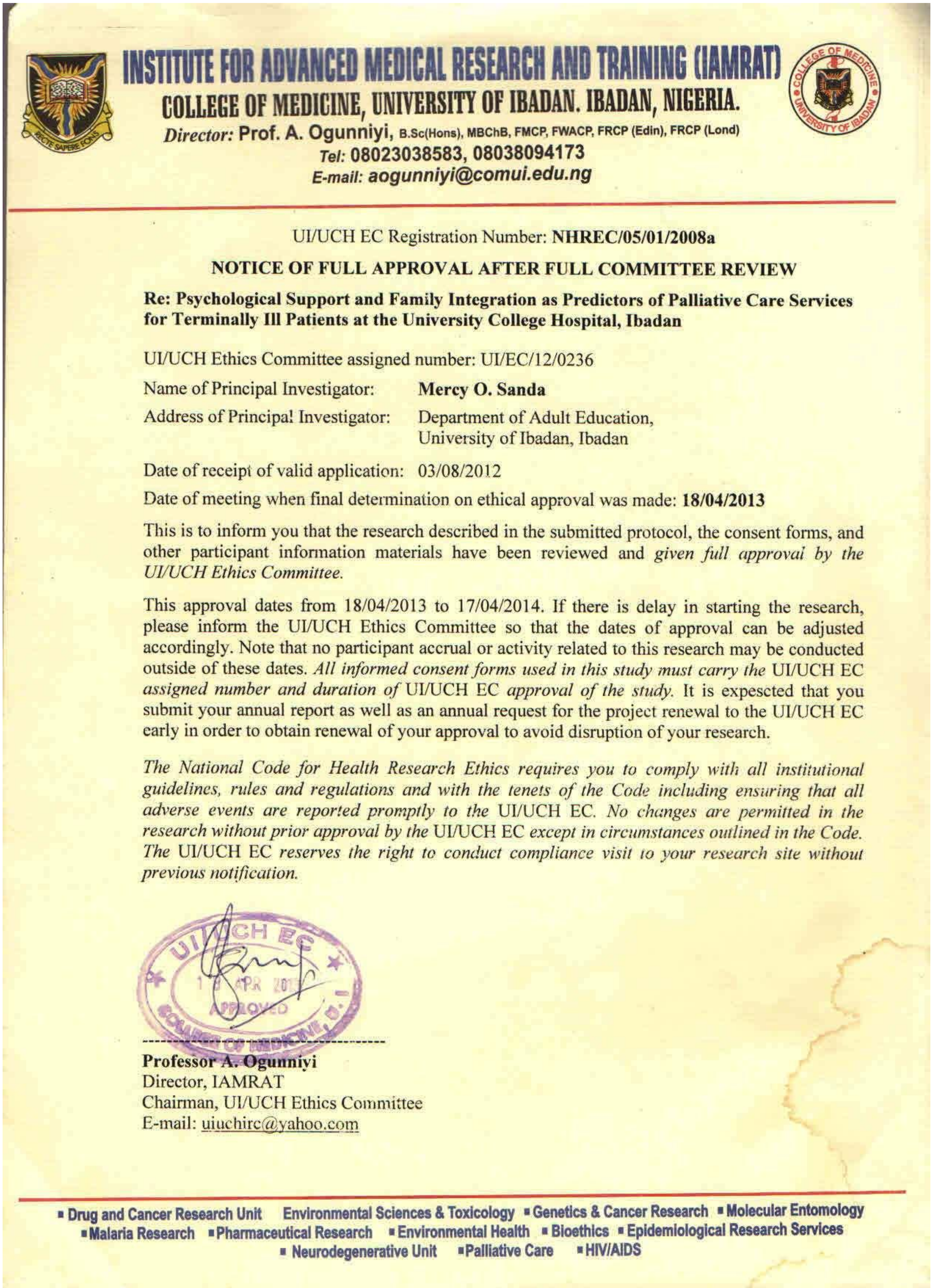

INSTITUTE FOR ADVANCED MEDICAL RESEARCH AND TRAINING (IAMRAT)
COLLEGE OF MEDICINE, UNIVERSITY OF IBADAN. IBADAN, NIGERIA.
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UI/UCH EC Registration Number: **NHREC/05/01/2008a**

NOTICE OF FULL APPROVAL AFTER FULL COMMITTEE REVIEW

Re: Psychological Support and Family Integration as Predictors of Palliative Care Services for Terminally Ill Patients at the University College Hospital, Ibadan

UI/UCH Ethics Committee assigned number: UI/EC/12/0236

Name of Principal Investigator: **Mercy O. Sanda**

Address of Principal Investigator:
Department of Adult Education,
University of Ibadan, Ibadan

Date of receipt of valid application: 03/08/2012

Date of meeting when final determination on ethical approval was made: **18/04/2013**

This is to inform you that the research described in the submitted protocol, the consent forms, and other participant information materials have been reviewed and *given full approval by the UI/UCH Ethics Committee.*

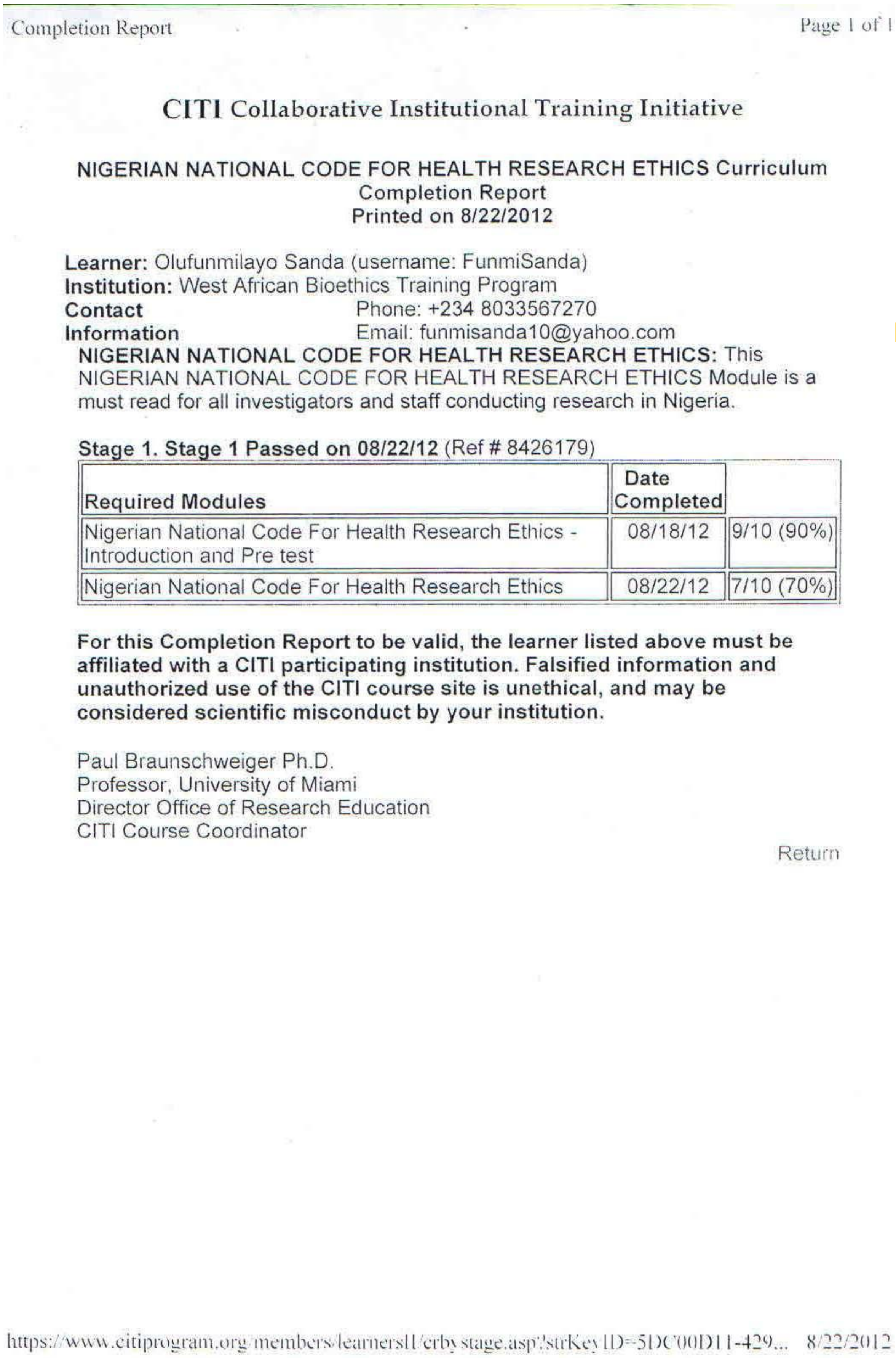
This approval dates from 18/04/2013 to 17/04/2014. If there is delay in starting the research, please inform the UI/UCH Ethics Committee so that the dates of approval can be adjusted accordingly. Note that no participant accrual or activity related to this research may be conducted outside of these dates. *All informed consent forms used in this study must carry the* UI/UCH EC *assigned number and duration of* UI/UCH EC *approval of the study.* It is expescted that you submit your annual report as well as an annual request for the project renewal to the UI/UCH EC early in order to obtain renewal of your approval to avoid disruption of your research.

The National Code for Health Research Ethics requires you to comply with all institutional guidelines, rules and regulations and with the tenets of the Code including ensuring that all adverse events are reported promptly to the UI/UCH EC. *No changes are permitted in the research without prior approval by the* UI/UCH EC *except in circumstances outlined in the Code. The* UI/UCH EC *reserves the right to conduct compliance visit to your research site without previous notification.*

UI/UCH EC
18 APR 2013
APPROVED

Professor A. Ogunniyi
Director, IAMRAT
Chairman, UI/UCH Ethics Committee
E-mail: uiuchirc@yahoo.com

■ Drug and Cancer Research Unit Environmental Sciences & Toxicology ■ Genetics & Cancer Research ■ Molecular Entomology ■ Malaria Research ■ Pharmaceutical Research ■ Environmental Health ■ Bioethics ■ Epidemiological Research Services ■ Neurodegenerative Unit ■ Palliative Care ■ HIV/AIDS



Completion Report Page 1 of 1

CITI Collaborative Institutional Training Initiative

NIGERIAN NATIONAL CODE FOR HEALTH RESEARCH ETHICS Curriculum
Completion Report
Printed on 8/22/2012

Learner: Olufunmilayo Sanda (username: FunmiSanda)
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NIGERIAN NATIONAL CODE FOR HEALTH RESEARCH ETHICS: This NIGERIAN NATIONAL CODE FOR HEALTH RESEARCH ETHICS Module is a must read for all investigators and staff conducting research in Nigeria.

Stage 1. Stage 1 Passed on 08/22/12 (Ref # 8426179)

Required Modules	Date Completed	
Nigerian National Code For Health Research Ethics - Introduction and Pre test	08/18/12	9/10 (90%)
Nigerian National Code For Health Research Ethics	08/22/12	7/10 (70%)

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Paul Braunschweiger Ph.D.
Professor, University of Miami
Director Office of Research Education
CITI Course Coordinator

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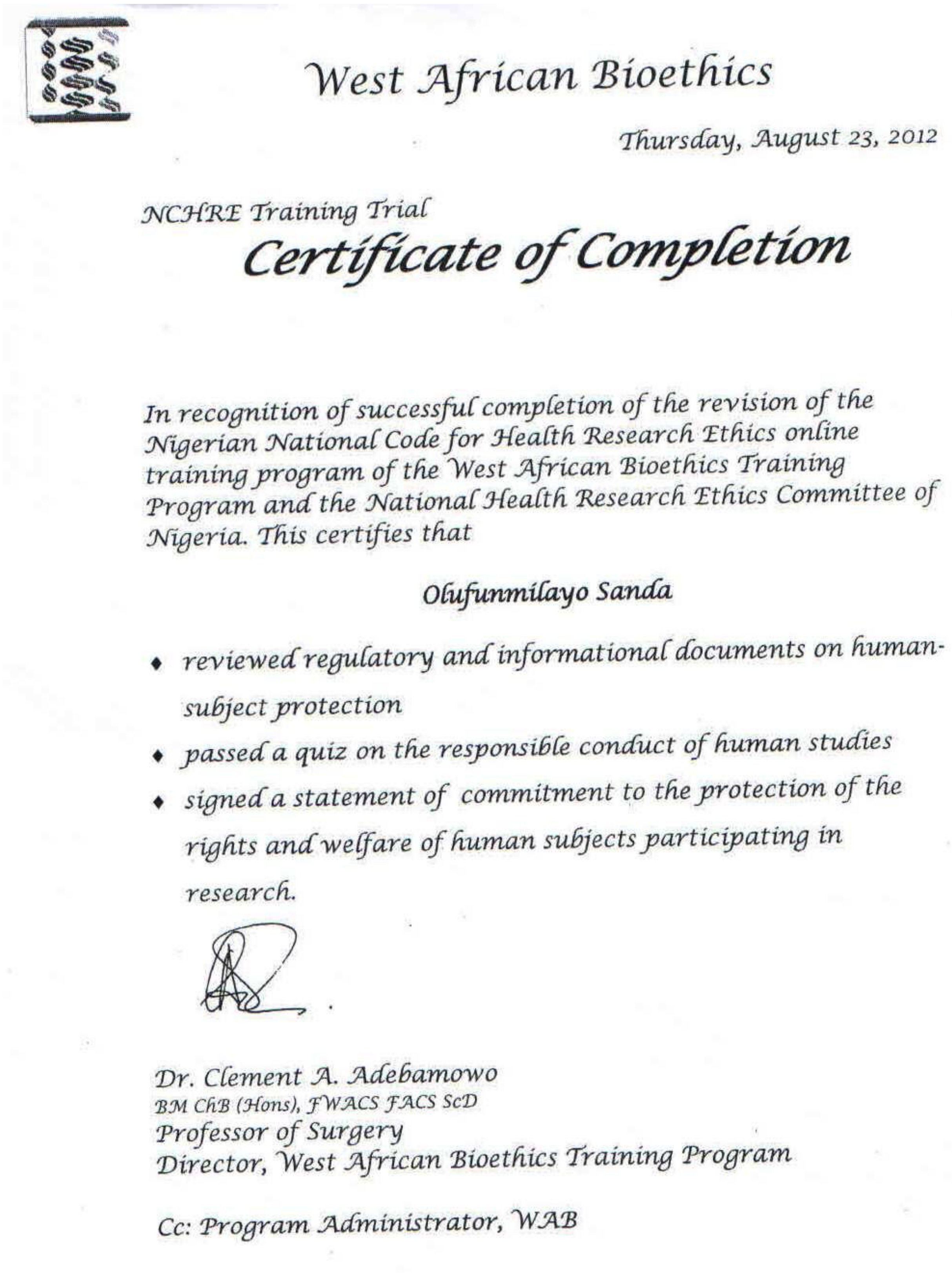

West African Bioethics

Thursday, August 23, 2012

NCHRE Training Trial

Certificate of Completion

In recognition of successful completion of the revision of the Nigerian National Code for Health Research Ethics online training program of the West African Bioethics Training Program and the National Health Research Ethics Committee of Nigeria. This certifies that

Olufunmilayo Sanda

- reviewed regulatory and informational documents on human-subject protection
- passed a quiz on the responsible conduct of human studies
- signed a statement of commitment to the protection of the rights and welfare of human subjects participating in research.

Dr. Clement A. Adebamowo
BM ChB (Hons), FWACS FACS ScD
Professor of Surgery
Director, West African Bioethics Training Program

Cc: Program Administrator, WAB