

**ASSESSING THE PALLIATIVE CARE NEEDS OF ELDERLY PATIENTS SEEN AT
THE UNIVERSITY COLLEGE HOSPITAL, IBADAN, NIGERIA.**

EUNICE NKECHI OMOYENI MBBS, MPH.

STUDENT NO: OMYEUN002

**SUBMITTED IN PARTIAL FULFILLMENT OF MASTER OF PHILOSOPHY IN
PALLIATIVE MEDICINE (MPhil Pall Med)**

**SCHOOL OF PUBLIC HEALTH AND FAMILY MEDICINE,
FACULTY OF HEALTH SCIENCES,
UNIVERSITY OF CAPE TOWN, SOUTH AFRICA.**



SUPERVISORS

A/PROF. LIZ GWYTHHER MBChB, FCFP, PhD.

Palliative Medicine

University of Cape Town,

Cape Town, South Africa.

PROFESSOR OLAITAN A SOYANNWO MMED, DA, FWACS, FICS.

HOPSICE AND PALLIATIVE CARE DEPARTMENT,

UNIVERSITY COLLEGE HOSPITAL

IBADAN, OYO STATE.

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Acknowledgements

To God Almighty, for giving me the grace, strength and health to complete this project and for journey mercies, to and from Nigeria.

To my supervisors, Professor Liz Gwyther and Professor Olaitan Soyannwo, for believing in me and teaching me “the how”, despite your busy schedules. Thank you so much for your words of encouragement.

To Professor Liz, a pillar of hope, strength and support. I bless the day I met you.

To Naomi Fray, for her continuous support and care.

To my loving, supportive husband, Pharm.Olayinka Omoyeni and understanding children (David and Favour). Thank you for your help, love and patience; for not complaining when I had to leave for contact workshops and when mummy had to do assignments.

To Bose, Mrs. Odu, Yemi, Newman and other research assistants: thank you for your time and input without which the data would not have been possible.

To the management at my institution, The University College Hospital: thank you for permission to travel to attend the contact workshops.

To my palliative care team members, thank you for your support.

I am so grateful to everyone who helped make this project a reality.

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Abbreviations/ Acronyms

APCA---- POS- African palliative care patient outcome scale.

ESAS---- Edmonton symptom assessment system.

GU---- Geriatric unit/ clinic.

HOPE---- Hope approach to spiritual assessment.

MOP---- Medical outpatient.

NCD ----Non communicable Diseases.

PC---- Palliative care.

UCH--- The University college Hospital.

Definition Section

Palliative care is “an approach to improve the quality of life of patients and their families facing problems associated with life threatening illness, through the prevention and relief of suffering, the early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”.¹

The **Elderly** have been defined in developed countries as people aged 65 years and above while in underdeveloped countries like in Africa, the term elderly is associated with pensionable age or when one becomes a grandparent like in Nigeria.

Advanced directive is a written statement of a person’s wishes regarding medical treatment, which often includes a living will, made to ensure those wishes are carried out should the person be unable to communicate them to a doctor.

Advance care planning is a process to help patients with decision-making capacity guide future health care decisions in the event that they become unable to participate directly in their care.

Abstract

Background

Nigeria, with a population growth rate (2000-2005) of 2.5% and with 5% of the total population aged 60 years and above, has the potential for a rapid growth rate of the older population in coming years.¹ The implication of this in a country with large population as reported by the National Population Census 2006, limited number of health care professionals and care homes, is difficulty in meeting the various needs of the elderly, hence, the importance of identifying the palliative care needs of the elderly.

Aim

The study was set out to assess the palliative care needs of and provision of care to elderly patients seen in the selected clinics of the University College Hospital, Ibadan, Oyo state, Nigeria.

Objectives

1. To describe characteristics of elderly patients seen in the selected clinics.
2. To explore the current use of the hospital palliative care team in the care of geriatric patient.
3. To explore the current use of the hospital palliative care team in the care of geriatric patient.

Methods

A descriptive cross-sectional study was conducted over a 3-month period using an interviewer administered questionnaire after full consent was given by participants. The questionnaire was a combination of the Africa Palliative Care Outcome Scale (APCA-POS), the Edmonton Symptom Assessment Scale (ESAS) and Hope Spiritual Assessment Tool. Demographic information regarding gender, age, nationality, abode and referral to the Care Centre was obtained. Scaled questions from selected tools were ticked with respect to physical, psychosocial and spiritual needs and expectations of palliative care. The validated data collection tools (APCA-POS, ESAS, HOPE) were used in the questionnaire. Ethical approval was obtained from the relevant organizations. Data was analysed using IBM SPSS statistics 21.

Results 424 participants completed the questionnaire and most patients (330; 77.8%) were recruited from the geriatric wards with a 2:1 female to male ratio. Most participants fell in the 60 -69 year-old age group. The most common symptom was pain in 240 patients with moderate pain in single or multiple areas. A high percentage (45.8%) were moderately worried about their disease condition and only 66 out of 422 freely discussed this feeling with their family members. Other symptoms observed were nausea, vomiting, constipation and loss of appetite.

Conclusion The study showed the palliative care needs of the elderly and calls for collaboration between the palliative care team and the physicians in the geriatric unit for better management of the needs of the elderly.

CHAPTER ONE

INTRODUCTION

1.1 Background

The World Health Organisation (WHO) defines palliative care as “an approach to improve the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering, the early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”.¹ Palliative care is the active total care of patients with serious and life-threatening illness, and involves a multidisciplinary approach to symptom management, maintenance of function and quality of life. In addition to a focus on relief and pain management, palliative care includes psychological and spiritual care, as well as bereavement and counselling as needed.

Palliative care is relevant to young and old patients which focuses on the relief of distressing symptoms and improving quality of life from the time of diagnosis through disease trajectory to the end of life.

The elderly have been defined in developed countries as people aged 65 years and above, while in underdeveloped countries such as in Africa, the term “elderly” is associated with pensionable age or when one becomes a grandparent in Nigeria. Although there are no standard criteria to describe the elderly by the United Nations, it is agreed that the age for the older population is 60 years and above.²

Elderly people often develop multiple chronic medical and non-medical problems, often arising from limited ageing regenerative abilities thus making them more susceptible to diseases such as hypertension, diabetes, arthritis, cataracts, hearing loss as well as dementia.

Chronic and life-limiting health problems in older individuals lead to poor quality of life, increased caregiver needs, loneliness, increased health care utilization, and sometimes institutional care. Hence, Dame Cicely Saunders, founder of the modern hospice movement, also included the care of older people in her vision for palliative care. The evidence of the need for Palliative care among the elderly brings to light the importance of assessing, and making available to elderly patients, holistic palliative care.

The importance of making available holistic palliative care was the focus of the 2014 World Health Assembly Resolution (WHA67.19) which was proposed and adopted after decades of

advocacy. The Resolution calls on WHO member states to work towards integrating palliative care into its national healthcare systems. Having considered the limited availability of palliative care services in most parts of the world – particularly in African countries with a high percentage of patients and their families suffering from life-limiting illnesses – the wording of the Resolution brings to light the need to establish and strengthen health care systems that include palliative care as an integral component, ensuring continuity of care to its citizens. Nigeria has a large population, poor health policies and limited resources, and is without doubt in need of the appropriate integration of palliative care in its health care system.⁴

This study was designed to assess the palliative care needs of elderly patients attending The University College Hospital, Ibadan, Nigeria. Very few elderly patients are referred to the palliative care unit/team and mostly for pain management, psychosocial and emotional assessment or support. This is a source of concern to the team, especially considering the multiple chronic morbidities of older people from the aging process and chronic illnesses. Thus bringing unwanted suffering, affecting their dignity, hence the importance of palliative care in addressing these multiple challenges affecting these elderly population through its holistic multidisciplinary approach.

1.2 Palliative Care for the Elderly – AN URGENT PUBLIC HEALTH PRIORITY

The World Health Organisation global statistics of those 60 years and older are increasing rapidly. In its publication on key facts on ageing and health, it stated that between 2015 and 2050, the proportion of the world's population over 60 years will almost double from 12% to 22%, with 80% of these older people living in low- and middle-income countries. The rapid increase in the population of elderly persons poses major challenges to all countries.⁵ This, in turn, highlights the importance of ensuring that the wellbeing of the elderly in matters of health and social needs is covered when taking this rapid increase into account. With the demographic shift, there will be an increase in demand at all levels of health care. There will be a special need for an improved, trained, multidisciplinary workforce.⁶

Nigeria with its large population, limited numbers of health professionals – especially in palliative care, no health policy for the elderly and changes in family demographics is faced with great challenges in identifying and addressing the needs of the elderly. These complex needs, together with the lack of palliative care knowledge and skills among health care professionals, leads to reduced quality of life and places additional burdens on available caregivers. In previous years palliative care was mainly for cancer patients, but its scope has widened and now includes care for the elderly.⁶

With the rapid growth in the number of older persons and the ageing process now complicated by chronic comorbid diseases as well as by psychosocial, spiritual and emotional needs, there is urgent need of increased access to palliative care for older persons, which includes those living with multiple comorbid disease/illnesses aside from cancer. A publication by Davies⁷ et al. stressed creating public awareness and an increase in health activities as playing a major part in the care of the elderly, especially those at the terminal phase of life.

Long ago, palliative care was thought to be unrelated to the promotion of health; however, both aspects of health have much in common. Both aspects look at health in totality in order to provide holistic care for elderly patients with long-term illnesses; hence, covering a wide range of needs of patients, caregivers and families rather than just the provision of clinical care. Palliative care focuses on symptom control, addressing needs pertaining to patients, caregivers and/or families and provides essential processes to help people live with and manage their situation, even among the elderly.

Palliative care for the elderly has become an important aspect of health care utilizing a

holistic approach, aiming to create and promote public policies for sustained health for the elderly. The priority includes creating supportive environments by strengthening community involvement in the care of the elderly, thus improving quality of life for older people under the motto “Dignified life till the end”.

This research study assessed and identified the palliative care needs of the elderly. The findings of the study will contribute to the development of programmes that have the potential to bring about improvement in direct palliative care service provision to the elderly in our institution and in Nigeria as a nation.

1.3 Global Palliative Care Picture

A number of publications have focused on the importance of, and need for, research in palliative care and palliative medicine for the geriatric population. With global ageing and scientific advances extending survival, the number of adults experiencing multiple chronic conditions has grown substantially and is projected to increase by another third between 2000 and 2030. These trends are requiring clinicians, health systems, and research institutes to shift from their traditional focus on individual conditions to an approach that encompasses a patient’s multiple health problems.^{8,9} Davies et al.⁷ maintain that older people have unmet needs in the areas of pain relief, information, communication and preferences for places of care. Similar studies also showed that there is evidence for the effectiveness of simple measures in the care of the elderly and for the role of coordinated team care, home nursing, and specialist palliative care services which, in our setting, includes hospice care, homebased care, psycho-oncology care, a day-care forum, palliative chemotherapy and radiotherapy, occupational therapy, a chaplaincy service which addresses their spiritual needs, and family conferences. As this evidence is based mostly on studies of older people with cancer; there are gaps in the evidence base for palliative care for older people with other serious chronic illnesses.¹⁰ A WHO publication titled better palliative care for older people in Europe showed that little is known of the palliative care needs and experiences of older adults.¹¹ This is supported by findings showing that the palliative care needs of older adults appear to be substantially different from those of younger patients.¹² Studies have also provided evidence indicating that dying elderly patients often do not receive appropriate palliative care at the end of life.^{13, 14}

The elderly suffer from an increased burden of chronic conditions of uncertain prognoses, make significant use of healthcare resources and their disease trajectory are often not adequately

communicated to them.¹⁵ The Second World Assembly on Ageing (8–12 April 2002, Madrid, Spain) adopted “an International Plan of Action on Ageing and a political declaration recommending that older persons must be full participants in the development process in the 21st Century”. Population ageing has been a prominent discussion in the major international population conferences and is addressed in other key UN declarations.¹⁶ According to the projections by the United States on ageing, there will be considerable growth in the older population between 2013 and 2050 in the United States. It is projected that in 2050, the population aged 65 years and above will be 83.7 million, almost doubling the estimated population of 43.1 million in 2012. The implications of this growth are the challenges that will arise for policy makers, families, businesses, health-care providers and Social Security. In 2013, the United Nations report on world population on ageing showed the global proportion of older people (aged 60 years or over) increased from 9.2% in 1990 to 11.7% in 2013, and this will continue to grow as a proportion of the total world population, reaching 21.1% by 2050.²

The number of older persons is projected to exceed the number of children for the first time in 2047. Currently, in underdeveloped regions, the population of the elderly is growing faster than in the developed regions.¹⁷ Most chronic illnesses in the United States, Europe, and in other developed countries occurs in those aged 65 years and older. These older individuals often live with and die from chronic illnesses that are preceded by long periods of physical decline and functional impairment. A study by Cartwright¹⁸ in 1991 on the changes of life and care in the year before death showed that people lived longer but with multiple prolonged and distressing symptoms. These findings were in correlation with the study by Solano et al.¹⁹ on symptom prevalence in advanced cancer and other life-limiting diseases among adults, including the elderly population. While taking into account the occurrence of distressing symptoms associated with cancer, Chronic Obstructive Pulmonary Disease (COPD) and other chronic life-limiting diseases, their study showed that pain, fatigue and breathlessness were the most prevalent symptoms among all groups – over 50% – followed by insomnia and anorexia.¹⁹ However, despite the high prevalence of the above symptoms, patients are poorly assessed and symptoms undertreated; hence, the relevance of palliative care (as defined by WHO) for these groups with an emphasis on good assessment and treatment including provision of home-based palliative care.

Elderly people also suffer from dementia, which can be very distressing for patients, and particularly for their families, and requires a holistic care approach through palliative care. The 67th World Health Assembly in Geneva titled “Strengthening of palliative care as a component

of comprehensive care throughout the life course” came up with a resolution that palliative care, when needed or indicated, should be recognised as fundamental to improving quality of life, wellbeing, comfort and human dignity for individuals. Being an effective person-centred health service, it values patients’ need to receive adequate, personally and culturally sensitive information on their health status, and values their central role in making decisions about the treatment received. This resolution highlighted the importance of palliative care for all ages – including for the elderly with co-morbidities as a result of the normal ageing process, chronic or life-limiting illnesses, and also highlighted their need for comfort, dignity, adequate information on their health status, input in decision-making on their treatment, their place of care and ensures that the patients’ documented health decisions are duly effected through the stages of disease progression. In caring for the elderly, palliative care is an important component of integrated medical and non-medical care treatment through the disease trajectory. With the projected increase in life expectancy and an increase in the size of the elderly population, health systems should be prepared to accommodate this projection, bearing in mind the ethical rights of the elderly to assess health care at any point in their disease trajectory. The ethical rights of the elderly to assess health care was also considered in the framing of the 2014 palliative care resolution, which acknowledged that palliative care is an ethical responsibility of health systems; it is the ethical duty of health care professionals to alleviate pain and suffering (physical, psychosocial or spiritual), irrespective of whether the disease or condition can be cured or not, and end-of-life care for individuals is among the most critical components of palliative care.⁴ The need for palliative care with ageing populations has increased and will continue to rise as a result of non-communicable and other chronic diseases in the elderly. The WHO resolution emphasizes the importance of palliative care and the need to adequately identify palliative care issues of ageing populations.

In 2012, WHO called attention to dementia as a public health priority. Dementia is an age-related health problem with a WHO estimation of people currently living with dementia worldwide to be 35.6 million, and is projected to double by 2030, and more than triple by 2050.²⁰ With the progression of dementia, elderly people affected by this disease will die with or from dementia as death with or from dementia markedly increases with age. The disease burden of dementia and other age-related morbidities among the elderly has great economic and global impact on families, caregivers, communities and the health system; hence the need for impeccable palliative care assessment and care for the elderly. In addition, providing holistic care for the elderly often involves crucial decision-making given the co-morbid conditions associated with

disease progression, ageing and patients' treatment desires. It is therefore important to establish goals of care relating to the older adult and therefore the need to assess general aspects of palliative care relevant to the geriatric population.²¹

1.4 Palliative Care in Africa

In Africa, even though palliative care started 35 years ago, with care associations in South Africa, Kenya, Mozambique, Rwanda, Tanzania and Uganda, its provision to the populace is still way behind when compared to developed countries. Palliative care provision, though inconsistent and provided by isolated Centres, has improved following the 2005 World Health Assembly, which identified palliative care as an urgent humanitarian need⁵. Palliative care is now delivered in nearly 50% of African countries though still facing challenges of acceptance into the various health systems.²⁰ Holistic palliative care assessment and services are crucial to caring for the elderly and are still lacking in the provision of palliative care in African countries where the major palliative care needs are pain and psychosocial issues including financial constraint and caregiver burden. Palliative care needs in Africa are complex and wide, which emphasises the importance of appropriate and effective implementation of government policies to cover and cater for the palliative care needs of the young and old living with chronic illness, particularly the elderly as their population is rapidly increasing and, if not addressed, will become a great burden to the relevant governments, health care professionals, families and care-givers.²²

In Uganda, palliative care is a priority in its National Health Plan, making palliative care initially available to a population of about 2 million people (Uganda's population is 22 million people). It is now available to about 5 million people, through the invaluable effort of Hospice Africa – Uganda established in 1993 in Kampala and now supported with two additional hospices.²² In 2009, a national policy was established by the Uganda government for older persons under the banner “Ageing with Security and Dignity” and this complements national health guidelines for providing comfort to older persons”.²² In line with the above policy for older persons, and with the assistance of the African Palliative Care Association (APCA) and the Palliative Care Association of Uganda (PCAU), the Geriatric Respite Care Foundation was founded in 2010 by Richard Semanda, a public administrator at Kampala International University, with the objectives to:

1. Establish a geriatric and palliative medical care facility to address the needs of older persons for health-ageing at the clinic and their needs at home
2. Provide quality care in a safe environment

3. Provide social activities geared to alleviating social isolation, such as pool table, lawn tennis, croquet and other indoor games
4. Provide training in self-care and modelling healthy eating practices
5. Assess the spiritual needs of elderly clients and plan for their health care as a result of spiritual needs.²³

These steps by this foundation have helped to improve the health and functional capability of older persons in society. Including palliative care in the Uganda National Health Plan has remarkably enhanced the provision of holistic palliative care services, in line with the cultural and practical needs of the elderly living with life-limiting illnesses. Today, Uganda is recognised as the mother of palliative care in Africa.

1.5 The Nigerian Picture

Nigeria, the most populous nation in Africa and ninth in the world, has a population growth rate (2000–2005) of 2.5%, with 5% of the total population aged 60 years and above – as published in the most recent national population census.²⁴ A rapid growth rate of the older population in the coming years is predicted with a lower growth rate among the younger population. This raises a difficulty in meeting the various needs of the elderly, with the limited number of healthcare professionals and care homes; hence, the importance of identifying the needs of the elderly.

Shofoyeke²⁴, writing in 2004, highlighted the Nigeria National Policy on Population (2004) which states that the elderly aged 65 years and above constitute about 3.3% of the population, and this is likely to increase in future. His appraisal found that apart from the multiple comorbidities faced by the elderly, there is poor support for the elderly particularly in accessing medical care. The overall health care system in Nigeria is a pay-for-service arrangement, which is limited to some types of illnesses or diseases. This fee-for-service system makes it more difficult for patients (including the elderly) with life-threatening conditions requiring expensive treatment to access care and it does not take into account health expenses.

Before the start of The National Health Insurance Scheme (NHIS) in 2003 Nigeria ranked 187 out of 191 countries in health care performance, with over 70% of health-financing being paid by individuals, with little or no community participation to health care. There was also no established broad-based health care financing strategy.¹⁰ The NHIS – which started in 2005 with the main goal of ensuring that every Nigerian had access to good healthcare services – is yet to achieve this set goal for the huge Nigerian population of over 170 million. There are also various

political challenges from each governing body. Although the Insurance Health Scheme has developed various programmes to cover segments of the population, the national health budget has always been insufficient for its purpose and has only covered 4% of Nigerians since its inception in 2005.²⁵ There is no private health insurance for people aged 60 and above in Nigeria; hence there are challenges faced by the elderly with virtually no policies addressing the welfare of elderly people.²⁶

The development of palliative care in Nigeria commenced in the 1990s and some authors have published reports covering several aspects of Palliative Care. Adenipekun et al.²⁷ examined the role of chemotherapy as adjunct to weak opioids for pain relief in patients with advanced cancer, while Elumelu et al.²⁸ presented experiences of the palliative care approaches in major hospitals in the south-western and eastern parts of Nigeria. Soyannwo et al. also wrote on “Palliative Care: Supporting Adult Cancer Patients in Ibadan, Nigeria, 2016” where the results showed the highest number of patients were in the elderly group (68%).²⁹

Although the development of palliative care in Nigeria started in the 1990s, the challenges and issues surrounding its integration into our health system have been enormous, coupled with poor awareness about palliative care. The available health policies did not address the need for palliative care services in the country until a few years ago when the Ibadan group, ably led by Professor Soyannwo, took up the need with government. Although palliative care is not yet in the medical fellowship programme of the country, it is gradually being seen as a needed specialty across all levels of the health care system in Nigeria.³⁰

The World Health Assembly Resolution WHA 67.19 urged member states to include palliative care as an integral component of ongoing education and training offered to care providers through basic, intermediate and specialist palliative care education through institutional or a nationwide taskforce. Nigeria as a member state is still faced with issues of resource-poor settings, cancer and HIV burdens, and non-inclusion of palliative care into the existing health system. Late presentation of patients to hospital, late diagnosis from inadequate tools, and a poor/epileptic electricity supply causing most hospitals and clinical laboratories (both government and private) to run on artificial electricity supply are additional health system challenges. These impact on the process of integrating and strengthening of palliative care as a model of care in Nigeria. There are also cultural and religious beliefs concerning sickness and death, including myths about opioid use (particularly for the elderly) that are barriers to the acceptance of palliative care. Cancer patients face inadequate supply, availability and the high cost of opioids as well as poor, limited radiotherapy intervention (very few radiotherapy machines in the whole country).³⁰

The basic training and continuing education on palliative care recommended in the WHA 67.19 Resolution which states that Palliative Care should be integrated as a routine aspect of all undergraduate medical and nursing professional education – is yet to be implemented in the various medical institutions in Nigeria. Through continuous advocacy, palliative care is now in the curricula of undergraduate medical student education at the University of Ibadan, which happens to be where palliative care was first introduced in the country.

The intermediate training (training at all levels of health care) described in the WHA 67.19 Resolution, should be offered to all health care workers who routinely work with patients with life-threatening illnesses – including oncology (adult and pediatric), infectious diseases, geriatrics and internal medicine – is faced with lack of awareness among health professionals and the stumbling block of institutional politics. Hospice palliative care training is yet to be incorporated into the current palliative care service as a result of lack of awareness about palliative care, lack of government support for palliative care and lack of funds for hospice start-up.

These issues serve as great challenges to the effective implementation and strengthening of palliative care as stated in the 2014 May WHA Resolution wherein member states were urged to develop, strengthen and implement palliative care policies appropriately in order to support holistic, effective and low-cost palliative care into the health systems at all levels of care (primary, secondary, community, tertiary and home-based care).³⁰

CHAPTER TWO

LITERATURE REVIEW

A literature search was done using search engines including Pub Med, PubMed Central, Google Scholar and Scopus to identify journals on the topic for this dissertation and for other relevant textbooks regarding palliative care and palliative medicine.

Since the specialties of palliative care, palliative medicine and geriatrics are still new in the institution (The University College Hospital) and in the country, there is no literature on the palliative care needs of elderly patients in Nigeria, although there are some publications on palliative care and pain management in Nigeria by Elumelu TN and Tonia C.^{28, 30}

2.1 Palliative Care Needs and the Rights of Older People

In the Universal Declaration on Human Rights, the elderly have an inherent dignity and right to life. Furthermore, the Declaration states that all human beings are born free and equal in dignity and rights, and that equality does not change with age; thus implying that the elderly have the same rights as people younger do.³¹ Although these rights do not change as we age, the elderly may be considered less productive and may be discriminated against; hence, the increasing challenges to their participation in their own wellbeing, which further serves as threats to their dignity and to violation of their rights.³¹

Palliative care is an interdisciplinary medical specialty that focuses on preventing and relieving suffering and supporting the best possible quality of life for patients and their families facing serious illness. The primary tenets of palliative care are symptom management; establishing goals of care that are in keeping with the patient's values and preferences; consistent and sustained communication between the patient and all those involved in his or her care; psychosocial, spiritual, and practical support both to patients and their family caregivers, and coordination across sites of care. Palliative care aims to relieve suffering at all stages of disease and is not limited to end-of-life care.³² The unmet needs among older people have been identified in areas of "pain relief, information, communication and preferences for place of care".

A pilot study carried out in a Swedish geriatric palliative care ward on elderly patients with "end-of-life" needs showed elimination of physical pain as the primary need of half of the elderly patients. Only when pain was eliminated or absent did other important needs (psychological, social, spiritual) frequently make themselves known; hence the need to adequately address these

unmet palliative care needs.³³ With global ageing and scientific advances extending survival, the number of adults experiencing multiple chronic conditions has grown substantially and is projected to increase by another third between 2000 and 2030. These trends are requiring clinicians, health systems, and research institutes to shift from their traditional focus on individual conditions to an approach that encompasses a patient's multiple health problems.^{33, 34}

A publication by Davies⁷ on the palliative care needs of older people and how they might be met showed evidence that elderly people have unmet palliative needs in the areas mentioned above. Changing the course of disease, particularly at the end of life, leads to the elderly living with chronic illnesses as well as with cancer; hence such older people have increased need for support and palliative care. However, palliative care has been neglected both in healthcare planning and in research. Currently, according to Davies⁷, awareness of palliative care among health professionals is still low. Elderly patients may become frail and their health may decline, resulting in dependence on others. Palliative care clinicians have an important role to play in helping elderly patients live fully in the time that remains and to achieve a death in comfort and with dignity.³⁵

2.2 Health Decisions for Older People

A paper titled “Research Priorities for Geriatric Palliative Care: Goals, Values, and Preferences” by Hanson in 2013, USA,³⁶ explained that older patients and their families desire control over health decisions when it comes to serious illness. Having achieved longevity, older persons often prioritize other goals such as function, comfort, family support and effective communication which are major aspects of palliative care. Palliative care physicians and palliative care teams are trained in communication skills. Hence, the importance of this research entity in older patients as effective communication has been identified as an unmet palliative need in the elderly.³⁶ Shared decision-making (as desired by patients and family) – as described in the WHO definition of palliative care – is the ideal approach in cases of serious illness. Although communication is vital in patient care, few participants from the study reported that clinicians discussed treatment options with them. It has been suggested that poor quality of communication adversely affects family satisfaction and patient outcomes.³⁷ This is reflected in elderly patients’ not having an advance care plan (where he/she makes decisions based on personal values, preferences, and discussions with loved ones/family members) while still competent to decide on the care they would like to receive in the event of becoming unable to speak for themselves as health deteriorates. This is a particular issue in Nigeria where cultural practices forbid talking about and planning for death or giving an advance care directive where the individual provides a written statement documenting his/her wishes concerning medical care. Such a directive often includes a Living Will and even when it is done, the details have to be communicated to the family head who might not communicate the patient’s wish after his or her death.

Karen et al.³⁸ studied the impact of advance health care planning on end-of-life care in elderly patients and showed that advance health-care planning improves end-of-life care, patient and family satisfaction and that such planning reduces stress, anxiety, and depression in relatives.³⁸ This is also in keeping with Kaldjian et al.³⁷ on goals of care at end of life wherein the following organized framework of the six goals of health care was proposed: curing disease, living longer, improving or maintaining function, being comfortable, achieving life goals, and providing support for family. When cure is not possible, the remaining medical goals – prolonging life, maintaining function or promoting comfort – are still relevant.

2.2 Planning Geriatric Services

In 2013, a study by Olden et al. explored geriatricians' experiences on palliative care for the older people and their results highlighted a number of needs of geriatricians working in acute geriatric care units. Recommendations are that there should be an action plan on palliative care and geriatric medicine to improve the quality of life of older patients with chronic diseases and to avoid emotional distress in caregivers.³⁹ This study emphasises the importance of palliative care in the geriatric population, as 90% of deaths across the Europe occur among people over 65 years, making it mandatory that these elderly age group get better access to palliative care. Furthermore, a shift has arisen in cause of death, unexpected death has largely been replaced by diseases with a much longer and more predictable end-of-life trajectory, such as cancer, cardiovascular disease or neurodegenerative diseases as dementia.^{40,41} Treating these patients' complex medical, social, psychological and spiritual needs requires adequate structures and state-of-the-art geriatric and palliative medicine. The hospital remains the predominant place of end-of-life care and death in Europe and between 63.9% and 83.7% of all non-sudden deaths occurring in a hospital setting. Since, in many European countries, older patients are cared for in acute geriatric care units, palliative care should be a matter of concern for geriatricians.⁴² In addition, Olden and colleagues³⁹ recommended that treating these patients' complex medical, social, psychological and spiritual needs requires proper identification of these needs which is why the identified tools for this study was chosen. Their findings explain that palliative care training should be mandatory in the education of each geriatrician in Europe and specific postgraduate course should be developed, as well as some specific textbooks adapted for this population.

A study by Kapo et al.³⁵ on palliative care for older adults explained that although geriatrics and palliative medicine share much in common, including an emphasis on optimizing quality of life and function, geriatric palliative care is distinct in its focus on the provision of care for chronic lifelong diseases which requires expertise in the diagnosis and management of these various health conditions seen in elderly adults. This expertise is essential in providing high-quality Palliative care to the elderly patient. Palliative care clinicians will increasingly be expected to provide care for the elderly adults to address their unmet palliative care needs.

It is therefore important to train both geriatricians in palliative care and other health care professionals (dietitians, physiotherapist, pharmacist, occupational therapist, clinical psychologist) who will be involved in the care of palliative care.

An increased intensity of care is required as health declines with age and additional problems arise such as dementia, delirium and falls. There is also a concern regarding polypharmacy to cope with co-morbidities and the possibility of adverse drug events. Hence the importance of palliative care for this age group, since palliative care is not just about the patient but include their families.

To address the unmet needs of the elderly for this study, palliative care tools that assess the physical, psychosocial, emotional and spiritual aspects were identified from the review of related studies on the research topic. These tools are the African Palliative Care Association (APCA) Patient Outcome Scale, the Edmonton Symptom Assessment Scale and the HOPE approach to Spiritual Assessment tool ([www.aafp.org/.](http://www.aafp.org/)) and were used in their original form without alterations. A publication by the African Palliative Care Association on the APCA African Palliative Outcome Scale showed that the tool may significantly advance the measurement, and improvement, of care for patients and families affected by life-limiting incurable disease, inclusive of older patients.⁴³

2.4. Rationale for the Study

Changes in the ageing process of the elderly, leading to chronic and/or multiple diseases as well as changes in disease progression, often affect the longevity of the elderly as well as their quality of life. The joy of growing old (or ageing) is truncated by physical, psychosocial, emotional and spiritual challenges of chronic/life limitation illnesses. The elderly, faced with such challenges, require holistic and compassionate care that will address the aforementioned needs, adding value and quality to life and preserving their dignity until the end of their lives. Provision of this holistic care for the elderly, who are mostly faced with non-communicable diseases, is a great gap in our health system in Nigeria, where there are no recognised health policies for the elderly.

Having understood the benefits of providing holistic care for the elderly through palliative care, its feasibility in Nigeria needs to be explored to enable healthcare providers to offer optimal holistic person-centred care for the elderly, given the competing health-care priorities and poor health policies for the elderly. Since the 2014 WHA67.19 Resolution focuses on health systems rather than on specific diseases, our institution (The University College Hospital, Ibadan) – which is the first to provide a palliative care service – will provide a platform for the implementation of this resolution.

Palliative care for the elderly was emphasized at the 2014 WHA discussion on non-

communicable diseases (NCDs) as a result of the increasing prevalence of NCDs and the rapid ageing of populations in the world. The resolution includes palliative care as an important part of the policy options proposed to member states and in its global monitoring framework by the WHO global action plan for the prevention and control of non-communicable diseases.⁶

The specialties of palliative care, palliative medicine and geriatrics are still new in the University College Hospital and the country as a whole. This study will help identify the needs of the elderly and serve as a driver to improving care and comfort through the provision of palliative care services to the elderly in selected clinics in UCH.

2.5 Aim of the Study

The aim of the study is to assess the palliative care needs of the elderly and their importance in planning services for the provision of care to elderly patients seen in the selected clinics of the University College Hospital, Ibadan, Oyo State, Nigeria.

2.6 Specific Objectives of the Study

1. To describe characteristics of elderly patients seen in the selected clinics
2. To assess the needs of the patients as relates physical, spiritual and psychosocial wellbeing.
3. To explore the current use of the hospital palliative care team during the care of the geriatric patient.

CHAPTER THREE

METHODOLOGY

3.1 Study Design

This is a descriptive cross-sectional study.

3.2 Study Location

The study was conducted at the medical outpatient, palliative care and geriatric clinics situated at The University College Hospital, Ibadan, Oyo State, Nigeria. The University College Hospital (UCH) Ibadan is a government-owned tertiary institution (a federal teaching hospital in Ibadan attached to the University of Ibadan). It was established in November 1952 in response to the need for the training of medical personnel and other healthcare professionals for the country and the West African sub-region.

The hospital has 60 departments among which are the clinics selected for this research – Medical Outpatient Clinic from the Medicine department, the Geriatric Clinic from the Geriatric department (the first and only geriatric department in the country), and from the Palliative Care Clinic in the Palliative Care department. The hospital operates a public care system with focus on general patient care, teaching through training, and research. It has a virology research laboratory, a WHO collaborating centre in Immunology and an Institute of Advanced Medical Research and Training (IAMRAT). Approval for research within the hospital is through the Institute of Advanced Medical Research and Training and the College of Medicine, University of Ibadan (affiliated with UCH.).

3.3 Study Population

The study population consisted of elderly patients aged between 60-80 years seen at the medical outpatient, palliative care and geriatric clinics at The University College Hospital (UCH), Ibadan. The study was conducted amongst a sample of patients who attended these clinics within the period of study, December 2015–February 2016.

3.4 Selection Criteria

3.4.1 Inclusion Criteria

Elderly patients aged 60 years and above attending/receiving care at the geriatric, palliative and medical outpatient clinics.

3.4.2 Exclusion Criteria

Elderly patients who were acutely ill, and too weak to communicate or too ill to respond to questions.

3.5 Sampling

A systematic sampling method was used to assess elderly patients who met the inclusion criteria from the selected clinics during the study period. The Leslie Kish sampling size formula estimation of single proportion was applied in getting the sample size.

The records from the clinics show an average of 50 elderly patients attended these clinics daily, giving us a total of 3000 patients that was seen during the study period. This gave a sampling interval (Kth) of 7.79 ~ 8. For practicality, every 5th patient was chosen to account for those that will not give consent to participate and those that might not continue after their Clinic session.

3.6 Data Collection Tools

An internet literature search was carried out to identify scholarly articles on the topic of palliative care and palliative medicine. Relevant assessment tools were identified from this search and applied in this study. The questionnaire tools identified from the literature survey were discussed with the research supervisor and the researcher's experience identified physical needs, spiritual needs and psychosocial needs of elderly patients necessary to answer the research question. These tools – African Palliative Care Association (APCA) Patient Outcome Scale, the Edmonton Symptom Assessment Scale and the HOPE approach to Spiritual Assessment tool⁴⁴ – are validated and reliable instruments, relevant to the selected study population in Nigeria and were all used in this study.

Harding et al.⁴⁵ in 2010 published a study – multi-centred involving five African countries – which was aimed at validating the ACPA African Palliative Outcome Scale as a multidimensional assessment tool. The study showed that APCA African POS has plausible quantifiable attributes (e.g., validity, reliability), showing its high levels of acceptability and adaptability in the African clinical setting, and thus making it suitable for use in our research setting.⁴⁵ The study also showed that the APCA African POS has a low mean and median time to complete: the values were mean 8–9 minutes and median 5–7 minutes. This clearly indicates that it is easy to be incorporated into routine patient clinical assessment.⁴⁵

In a study by Bausewein et al.⁴⁶ on outcome measurement in palliative care where a

number of tools used for measuring outcomes – including the Palliative Care Outcome Scale (POS) and the Edmonton Symptom Assessment Scale (ESAS) – were looked at, the APCA-POS and the Edmonton Symptom Assessment Scale were found to be multidimensional, easily accepted and brief to complete. The ESAS took approximately 5 minutes to complete and the POS scale's mean time for completion by patients was 6.9 minutes and 5.7 minutes by staff. The tools were noted to be available in a wide range of languages, broadly validated and used widely in palliative care.⁴⁶

Gowri A⁴⁴ described the contents of the HOPE assessment tool as “H” defining sources of hope, strength, comfort, meaning, peace, love and connection; “O” as the role of organized religion for the patient; “P” defines the patient's personal spirituality and practices, and “E” as the effects of their spirituality on medical care and end-of-life decisions.

The HOPE assessment tool gives room for an open-ended exploration of an individual's general spiritual concerns and resources, which then opens an opportunity for natural follow-up and discussion of spiritual support systems. Its open-ended explorative nature made the HOPE spiritual assessment tool very easy for participants to understand and to easily accept as it addressed the spiritual aspects of our religious beliefs and practices in Nigeria. The HOPE tool, therefore, assesses the spiritual sources of hope, strength, comfort, meaning, and the role of organized religion as it relates to participant's personal spiritual practices and their effects on medical care and end-of-life decisions.⁴⁰

Although these tools have high recommendations for research, a study done by Downing J et al.⁴⁷ in 2012 on the selection and implementation of outcome measures found some challenges experienced by participants on the use of the APCA-POS. This included findings such as participants' family members not wanting to comment when asked about whether they had received help and advice to plan for the future as the question was interpreted as though the patient was about to die. Some complained of language barriers some noted lack of time to complete the tool; some complained about the ratings for the symptoms addressed in the tool (some symptoms were rated best to worst at 0–5, while some were rated worst to best) and another finding was the inability of some respondents to complete the tool as a result of low literacy levels and frailty.⁴⁷ The study also showed that aside from the above-mentioned challenges, the tool was the most frequently used and was viewed as being very reliable. It was also encouraging to see that a variety of tools are being used in clinical care and research in the African region.

3.7 Recruitment of Participants

Once the study itself was approved and ethics approval given, a letter for permission to conduct research was written to the departmental heads whose clinics were used as the research site. Once permission was received, the study was introduced to the medical and non-medical staff within the clinics and a copy of the certified letter of approval was given to the Chief Nursing Officer (CNO) in charge of the clinics.

Patients attending clinics chosen as the study sites were then approached to participate in the study after the CNO gave a health talk to the patients and also introduced the research team (i.e. the research assistants and the investigator). Thereafter, the researcher addressed all the patients in the waiting room of the clinics on the importance of the study at each clinic. This was done daily with in the study period and were encouraged to ask questions. The address and question-and-answer session were carried out before the consultation period while patients' case records were being sorted.

Thereafter, patients were approached individually by the research assistants and a full explanation of the study was carried out in the potential participants' own language using the Information sheet Appendix 1. Potential participants (those who showed interest after the general question and answer session) were given the opportunity to ask additional questions about the study. Participants were allowed to choose whether or not to participate in the study and were told they may withdraw at any time during the course of study without any repercussion. Participants were then asked to sign voluntary consent forms for the research to go ahead.

About 30% of the patients approached did not consent to participate in the study, which was mostly due to the carers not based in the Ibadan and they have to leave immediately after the doctor's consultation. While about 70% of elderly patients agreed to participate in the study after full explanations about the study was given to them.

3.8 Data Collection Process

Research assistants were recruited into the study through the Palliative Care department from the records of those that had received formal training in palliative care. The research assistants, once selected, were trained on professionalism and the required sensitivity to study participants especially because of their age group and health status. They were also trained on research ethics; the methodology of the study, including selection criteria; the mechanics of voluntary participation; the importance of each section of the questionnaire, and how to obtain

informed consent from the patient and how to administer the questionnaire.

Trained research assistants then administered questionnaires to those patients who had consented to take part in the research study. Data was collected using an interviewer-administered questionnaire (see Appendix 2). Information on the socio-demographic characteristics, the source of referral and the participants' prior knowledge about palliative care were recorded. The African Palliative Care Association (APCA) Patient Outcome Scale assesses the physical and psychosocial symptoms which include pain, nausea, constipation, coughing, worry, being at peace and family support. (Appendix 2). The Edmonton Symptom Assessment Scale [ESAS] assesses psychosocial and emotional symptoms which includes-nausea, tiredness, feeling of depression, drowsiness, and feeling of wellbeing. It also assesses physical symptoms of pain and breathlessness. The ESAS has attached to it a body image for physical representation of pain site/s (Appendix). It is of note that the APCA POS and the ESAS symptom assessment tool ratings are slightly different, though both rate quality of outcome in increasing number, relating higher score to better outcome. (Appendix 2).

3.9 Conducting the Interview

The interview was conducted in a comfortable place within the various clinics and available consulting rooms. A simple explanation of the aim and methodology of the study was given to willing participants in their mother tongue. Since the Chief Nursing officer (CNO) was aware of the study, none of the participants missed their clinic appointments. If any patient became too ill to continue answering questions, the research assistant stopped the interview. Questionnaires were interviewer-administered by the investigator and the research assistants recruited into the study.

During the course of the interview, if the research assistant identified any distressing symptom based on verbal communication from a participant or the attribution of a score, she informed the CNO and the researcher, who then addressed it with the primary physician in the clinic. Thereafter, the findings were referred to the palliative care team by the physician once the need for continuing palliative care service was identified.

3.10 Data Storage and Confidentiality

Data collected by the research team was securely held under authority of the records assistant of our palliative care unit throughout the period of study. A secure code was also put in place when logging the information into the software of the computer system and the completed

questionnaires were kept in a secure locked cabinet. The electronic data on the system was password protected to ensure confidentiality.

3.11 Data Analysis

The data collected during the interviews was keyed into a Microsoft Excel spread sheet. Questions on each tool were coded with numerical values. Statistical Package for Social Sciences (SPSS) software was used to compute and analyse the data after collation. Frequencies, percentages, means and standard deviations were calculated. Analysis of each aspect of the questionnaire was carried out to probe if the elderly had distressing physical, psychosocial and spiritual symptoms – pain, anxiety, constipation, financial constraint, communication problems, loss of meaning to life, loss of hope, anger and other variables.

3.12 Ethical Considerations

Ethical approval for the study was obtained from the Human Research Ethics Committee of the University of Cape Town, South Africa as well as from the UHT the Ethics Review Board, Nigeria. Permission was also received from the heads of the geriatric, medical outpatient and palliative care clinics at the hospital.

The study took into account the vulnerabilities of the study population, including lack of support resulting from ageing and comorbid chronic conditions, physiological changes, changes in cognitive ability and communication difficulties. The latter could impinge on their decision to participate. Special consideration was also taken to ensure convenience for the participants.

The study population required clear explanation and frequent checking of their understanding, and a distress protocol was put in place. Participants were advised to call the telephone/mobile contact of the researcher – written on the first page of the questionnaire when in distress – and they could also call the CNO in charge of the clinic where they were. In taking into account the patients' vulnerabilities, the research assistants were instructed to stop interviewing any participant who become emotionally or psychologically distressed at any point. The research assistants were asked to inform the CNO in charge and to also call the attention of the researcher, who then contact's the clinician in charge of the patient. Participants could also call the contact number on the consent form as stated previously during the execution of this study, none of the participants suffered any form of distress.

CHAPTER FOUR RESULTS

TABLE 4.1.1 SOCIO-DEMOGRAPHIC DATA OF GENDER AND AGE

VARIABLES	FREQUENCY (N)	PERCENTAGE (%)
Gender		
Male	167	39.4
Female	257	60.6
Age		
60–69	216	50.9
70–79	149	35.1
80–89	55	13.0
90–99	4	0.9

More than three quarters of the study sample (77.8%) were recruited from the geriatric outpatient unit; 20.3% from the medical outpatient unit and 1.9% from the palliative care outpatient unit. About half (50.9%) were in the 60–69 years age range; 60.6% were females and 33.3% had attained secondary level education. The high number of participants from the geriatric outpatient clinic was due to the existing Hospital policy of all patient from 60 years of age and above are first seen at the geriatric clinic which has all specialties aside Palliative Care.

TABLE 4.1.2 SOCIO-DEMOGRAPHIC DATA – CONT.

VARIABLES	FREQUENCY (N)	PERCENTAGE (%)
Clinic		
Geriatric	330	77.8
Medical outpatient	86	20.3
Palliative care	8	1.9
Marital Status		
Single	5	1.2
Married	250	59.0
Divorced	32	7.5
Widowed	124	29.2
Separated	13	3.1
Ethnicity		
Yoruba	395	93.2
Igbo	22	5.2
Hausa	2	0.5
Others	5	1.2
Level of Education		
None	110	25.9
Primary	75	17.7
Secondary	141	33.3
University	77	18.2
Other	21	5.0

TABLE 4.1.3 SOCIO-DEMOGRAPHIC DATA CONT.

VARIABLES	FREQUENCY(N)	PERCENTAGE (%)
Place of Abode		
State	104	24.5
Town	320	75.5
Referred by		
UCH	111	26.2
Private hospital	37	8.7
Self	261	61.6
Others	15	3.5
Previous Knowledge about Palliative Care		
Yes	67	15.8
No	357	84.2

TABLE 4.2 DIAGNOSIS OF RESPONDENTS

DIAGNOSIS	FREQUENCY (N)	PERCENTAGE (%)
Cancer	15	3.5
Cardiovascular disease	101	23.8
Chest infection and cough	11	2.6
Diabetes	36	8.5
Eye problem	23	5.4
GIT and liver diseases	2	0.5
Hypertension	2	0.5
Kidney problem	2	0.5
Multiple illnesses	123	29.0
Others(awaiting diagnosis)	109	25.7

TABLE 4.3 RESULTS OF AFRICAN PALLIATIVE CARE ASSOCIATION (APCA) PATIENT OUTCOME SCALE (POS) SURVEY

	0		1–2		3–4		5	
	(None)		(Mild)		(Moderate)		(Overwhelming)	
	N	%	N	%	N	%	N	%
Pain	80	18.9	61	14.4	240	56.6	43	10.1
Other symptoms	205	48.3%	104	24.5%	107	25.2%	8	1.9%
Worry	63	14.9%	156	36.8%	194	45.8%	11	2.5%
Ability to share	16	3.8%	54	12.4%	288	66.4%	66	15.2%
Life worthwhile	60	14.2%	155	36.6%	175	41.3%	33	7.7%
At peace	7	1.6%	71	16.4%	309	71.2%	37	8.5%
Enough help & advice	12	2.8%	77	18.2%	290	68.4%	45	10.6%

KEY

Pain- 0 (no pain) - 5 (worst/overwhelming pain)

Worry- 0 (not at all) - 5 (overwhelmingly)

Other symptoms- 0 (not at all) - 5 (overwhelming worry)

Life worthwhile - 0 (no, not at all) - 5 (yes, all the time)

At peace - 0 (no, not at all) - 5 (Yes, all the time)

Table 4.3 shows that 56.6% of the respondents had moderate pain, 10.1% had severe to overwhelming pain and 18.9% experienced no pain. Worry assessment revealed that 45.8% were moderately worried about their disease condition while 14.9% had no form of worry/concern about the disease condition. Spiritual measures showed that patients felt that life is worthwhile (49%) and 79.7% felt at peace. Most patients reported that they had sufficient help and advice to plan for the future.

TABLE 4.4 RESULTS OF EDMONTON SYMPTOM ASSESSMENT SCALE (ESAS – NS) SURVEY

	None N (%)	Mild N (%)	Moderate N (%)	Severe N (%)	Worst possible N (%)
Pain	74(17.5%)	26(6.1%)	154(36.3%)	137(32.3%)	33(7.8%)
Tiredness	92(21.7%)	106(25%)	187(44.1%)	35(8.3%)	4(0.9%)
Nausea	371(87.5%)	31(7.3%)	14(3.3%)	7(1.7%)	1(0.2%)
Depression	95(21.9%)	174(40.1%)	137(31.6%)	16(3.7%)	1(0.2%)
Anxiety	344(81.4%)	39(9.2%)	33(7.8%)	6(1.4%)	1(0.2%)
Drowsiness	367(86.6%)	26(6.6%)	21(5%)	4(0.9%)	4(0.9%)
Appetite	323(76.2%)	55(13%)	30(7.1%)	12(2.8%)	4(0.9%)
Feeling of wellbeing	191(45.1%)	168(89.6%)	52(12.3%)	9(2.1%)	4(0.9%)
Shortness of breath	389(91.7%)	20(4.7%)	7(1.7%)	6(1.4%)	2(0.5%)
Other problems	205(48.3%)	104(24.5%)	107(25.2%)	8(1.9%)	0(0%)

Table 4.4 shows the results of the ESAS – NS questionnaire which describes physical and psychological symptoms and considers a wider range of these symptoms than POS. The most significant clinical problem recorded was pain with 76.4% of participants describing pain as moderate, severe or worst possible pain. Other problems or symptoms as described by participants were constipation, cough, nausea, headache, fatigue and diarrhoea. Participants described fatigue as extreme tiredness, having no energy at all.

TABLE 4.5 SITES OF PAIN USING THE EDMONTON SYMPTOM ASSESSMENT SCALE

PAIN SITES	FREQUENCY (N)	PERCENTAGE (%)
Head and neck	26	6.1
Upper limb	57	13.4
Lower limb	38	9.0
Waist/back	23	5.4
Knees	21	5.0
Multiple sites	171	40.3
No site of pain	88	20.8

According to Table 4.5, 40.3% had pain in multiple sites while 13.4% had pain in the upper limb and 88(20.8%) had no other site of pain.

TABLE 4.6.1 SPIRITUAL ASSESSMENT USING THE HOPE APPROACH TO SPIRITUAL CARE

HOPE ASSESSMENT TOOL	FREQUENCY	PERCENTAGE (%)
HELP IN DIFFICULT TIME		
God	421	99.3
God and family	2	0.5
Hope in God	1	0.2
MEMBER OF AN ORGANISED RELIGION		
Yes	337	79.5
No	87	29.5
SPIRITUAL BELIEF		
Yes	3	0.7
No	421	99.3
IMPORTANT RELIGIOUS PRACTICES		
Evangelism	2	0.5
Five-times prayer	1	0.2
Going to Mecca	2	0.5
Praise	1	0.2
Prayer	412	97.2
Prayer and fasting	1	.2
Prayer and praise	2	.5
Prayer and service	1	.2
Service attendance	2	.5

TABLE 4.6.2: SPIRITUAL ASSESSMENT USING THE HOPE APPROACH TO SPIRITUAL CARE CONT.

HOPE ASSESSMENT TOOL	FREQUENCY (N)	PERCENTAGE (%)
MOST HELPFUL SPIRITUAL PRACTICES		
Prayer	421	99.3
Prayer and fasting	2	0.5
Prayer and praises	1	0.2
CONFLICTS BETWEEN BELIEFS AND CARE		
Yes	1	0.2
No	423	99.8

BELIEFS THAT MAY AFFECT CARE

Yes	337	79.5
No	87	29.5

**WISH TO CONSULT A RELIGIOUS
LEADER**

Yes	36	8.5
No	338	91.5

CHAPTER FIVE

DISCUSSION

5.1 Referrals and Awareness

This research study was undertaken to establish baseline data on the palliative care needs of the elderly at the University College Hospital (UCH), Nigeria. The study recruited participants from the medical, palliative care and geriatric outpatient clinics. It appears that there is good awareness of the available geriatric service but poor awareness of the availability palliative care services. The awareness about geriatric service is due to the Hospital policy that all patients aged 60years and above must first be seen at the geriatric outpatient clinic except in cases of emergency. Lack of awareness about palliative care is shown by the response to the questionnaire that few people have heard about palliative care, hence the poor referral to the palliative care outpatient clinic. Another reason for the poor referral to the palliative care team is the fact that most of the medical specialities are available in the geriatric centre apart from palliative care which at the time of this study is not among the available specialties in the geriatric centre. What is necessary is an increased and improved understanding of the palliative care needs of the elderly in view of the rapid growth in the population of older adults in particular, as well as the increasing palliative care needs among the older age groups.^{48,49}

A significant number of older people presented with pain as the major reason for attending the clinics. The analysis of the physical and psychosocial assessment revealed that over two-thirds of the participants had moderate to severe/overwhelming pain.

Pain is a major distressing symptom among the elderly, greatly affecting their quality of life. Worldwide, pain is under-treated, and this is particularly true of pain in the elderly as described by Davies⁷, which showed pain relief as one of the unmet palliative care needs of the elderly. Other unmet needs were the necessity for information, sensitive and factual communication about the illness, and asking people where they would choose as their place of care.

5.1.1 Dealing with Pain

In keeping with international studies, this research identified pain as the most significant and distressing symptom among the elderly. When assessed by both APCA POS and ESAS, a high number of participants were found to have moderate to severe pain, which is in keeping with the study by Davies et al ⁷ which described pain as one of the unmet palliative care needs of the elderly. This calls for improved and proper assessment of pain among this age group as it has been identified as the most distressing symptom and greatly affects morbidity.

Pain among this age group maybe due to other co-morbid conditions and the changing course of disease especially at the end of life. These two factors further underscore the increased need for support and palliative care for the elderly, as seen in table 4.2 where a high number of participants- 123(29.0%) had multiple illness requiring a holistic approach to care. Table 4.5 also highlighted a high number of participants with multiple sites of pain-171(40.3%) which may be due to the multiple comorbid conditions.

The physical assessment from the study showed pain at multiple sites; this is likely to be due to the presence of co-morbid condition such as arthritis, diabetes, and to normal ageing processes with degenerative conditions and life limiting-illnesses such as cancer. Ferrell stated that Pain is the most common complaint in physicians' offices among older patients.⁵⁰

Cartwright¹⁸ reported that longevity was associated with multiple prolonged and distressing symptoms, which also correlates with the findings in a study by Solano et al.¹⁹ “which showed that pain, fatigue and breathlessness were the most prevalent symptom among all groups, over 50”. Helme⁵¹ stated that “older people often experience chronic pain in the joints, back, legs, and feet, which reflects the plateau in overall chronic pain prevalence with age”. The authors describe pain at multiple sites as “a possible reflection of balance between age-related impairment of the nociceptive function of the nervous system and an increase in the pathological load that accompanies old age”.

In Nigeria, cultural and religious practices affect the way pain is viewed and treated among adults. Culturally, pain is seen as a symptom to be endured as sign of maturity and, among the elderly, as a sign of the normal ageing process. Complaints of pain among the elderly are sometimes seen as a way of attracting attention, especially for elderly people whose children live far away from them: this may lead to under-reporting and under treatment of pain. Pain among the elderly sometimes leads to increased caregiver needs, which also leads to caregiver burden and increased financial expenses for the carer. Although this study assessed presence of pain, Saunders et al stated in their publication that pain leads to anxiety, loneliness and possible increased health-care utilization by the family caregiver as well as by the patient.⁵² Table 4.4 showed some participants had mild to moderate anxiety 39(9.2%),33(7.8%) in keeping with the publication by Saunders et al.

Pain is a debilitating symptom and, as such, should be effectively managed. Kaldjian et al.³⁷ in 2008 advised that an organized framework of goals of care toward the end of life included improving or maintaining function and being comfortable should be one of the five goals. Effective pain control which can be offered to these elderly patients by the trained palliative care physician and team will help promote comfort.

A study showed that caregivers tended to underestimate the severity of pain.⁵²² Pain is a subjective experience and palliative care practitioners emphasise that the patient's report should be the measure of pain so that the observer, whether clinician or family member, should not discount the patient's report. Frequently, pain in the elderly as reported by the caregivers depends on the caregiver's sensitivity as a result of the belief that the patient, because he or she is elderly, might exaggerate the pain symptom. This disrespects the patient and undermines his or her autonomy. It is important that elderly patients are allowed to describe their pain according to their experience and understanding as seen in the pain results in tables 4.3 and 4.4, using the APCA-POS and ESAS scales. The 2-4% difference in the pain reports could have risen from the presence of the ESAS pain site chart which gave a high % of those with multiple sites of pain as the participants could localize the area of pain on the chart thus giving a lower % of those with mild to moderate pain the ESAS as compared to the APCA POS with higher %.

Pain is a holistic experience and, as such, a multidisciplinary team approach should be instituted in the management of pain in these patients – which is exactly the approach used by the palliative care team, hence the importance of palliative care for the elderly.

Dame Cicely Saunders stated that her original 'vision' included the care of older people "which should not be a facet of oncology alone but of geriatric medicine, neurology, general practice and throughout medicine".⁴⁸ This, therefore, emphasises the tight links that should exist between the specialities involved in caring for the elderly as evident by the palliative care need among older people. In Nigeria and in our institution, UCH, where palliative care is a new speciality and there are few trained palliative care health professionals, there is still a huge gap in knowledge about the available palliative care services even among other health care professionals within the institution.

In Nigeria, palliative care for the elderly, through a multidisciplinary approach by government and the private sector, is a vital specialty needed in the provision of effective healthcare. A study by Elumelu et al.⁵³ revealed that in addition to the gap in knowledge about palliative care, there is also reluctance by doctors in Nigeria to prescribe morphine where it is available because of misconceptions such as the fear of addiction and the fear of it leading to death among the elderly. Their study showed that only 1.1% of oral morphine was prescribed for the management of chronic pain according to World Health Organisation standard.⁵³

Most morphine is prescribed in surgery for surgical procedures and management of post-operative pain. Worldwide, morphine and other opioid medications have been shown to be safe, effective and inexpensive (in the case of morphine) medication for the management of pain. The INCB and WHO encourage the balanced use of opioid medication to ensure that patients in pain

receive relief from this debilitating symptom. It is only in North America where opioids are used inappropriately that reports are received about an increase in deaths due to this inappropriate use. The danger for the rest of the world presented by the prescribing patterns in the USA is that opioids will be further restricted in countries where there is undertreatment of pain.

The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) identifies pain relief in the elderly “as a right and requires facilities to implement specific procedures for, and provider education on, pain assessment and management”.^{54,55} Attending to pain, therefore, is an unmet palliative need in the elderly that should be properly assessed and treated. Palliative care and geriatric care, both using a multidisciplinary model of care, have similar input on quality of life concerning the patient and family. As stated earlier, effective pain relief in the elderly requires proper pain assessment and management.

Some epidemiological studies of untreated pain in the elderly present between 25% and 50% among community-dwelling elderly people, and up to 83% of the institutionalized elderly.^{56,57} Poorly treated pain can lead to complications particularly in elderly patients with multiple chronic diseases such as arthritis, cancer, pneumonia, constipation, or deep vein thrombosis, prolongation of illness, and increased hospital stays.⁵⁷ While proper pain assessment is crucial in maintaining the quality of life in the elderly, it is also important to be on the lookout for misconceptions, such as cultural, religious or personal beliefs, that can lead to undertreatment of pain. Some misconceptions among elderly patients, particularly in our setting (Nigeria), include beliefs that that pain is unavoidable; that pain is for a reason; that pain is a punishment (particularly in cancer patients who feel they have offended God), and that pain medications, such as morphine, are addictive.

The health care professional can also hold some misconceptions about pain assessment and treatment, which leads to the under-treatment of pain. Some of these beliefs include that elderly patients have decreased sensations of pain, or that they have a low pain tolerance. There is also a perception that the elderly complain more about pain as they age. In addition, there is also inadequate training about pain management that has led to a belief that opioids (such as morphine) can hasten death or can cause respiratory depression.⁵⁷ Thus, there is a need to educate doctors on the safe use of opioids starting with a low dose of morphine administered orally and titrating the dose of morphine required to control the pain to prevent unwanted side effects.

In summary, it is imperative to take elderly patients' reports of pain seriously and to manage pain effectively. As seen in the review of previous studies done on the palliative care needs of the elderly, older people with chronic, life-limiting illnesses have high prevalence of symptoms relating to the disease condition or to the ageing process.

5.1.2 Dealing with Other Symptoms

Walke et al.⁵⁸ illustrated in their study on the frequency of symptoms in community-dwelling elders aged 60 or older –with advanced chronic obstructive pulmonary disease (COPD), heart failure (HF), or cancer – that a high number reported a symptom rating of “moderate to severe” while others reported at least two such symptoms.⁵⁸ Our research study concurs with the findings of the Walke study, where a significant number of participants reported other distressing symptoms aside from pain and rated these symptoms as “moderate” and some reported these symptoms as “overwhelming”. The symptoms included constipation, nausea, cough, fatigue, breathlessness and loss of appetite, with limited activity and physical discomfort (from pain, constipation, breathlessness) being the most common.⁵⁸ Such symptoms are not unusual in malignant and non-malignant diseases, for co-morbidities such as diabetes mellitus, chronic hypertension, infections and physiological changes are associated with ageing.

Our findings on what participants were treated for showed that the highest number had multiple illnesses, followed by cardiovascular diseases, diabetes and eye problems – which are often interrelated. The symptoms as described above may be interwoven into what the participants reported as “multiple illnesses”.

Constipation as a symptom in elderly patients may be cancer-related, (gastric, intestinal cancers, metastatic and gynaecological cancers), or arise from reduced activity, weakness, dehydration and poor nutrition, use of opioids, antihypertensives, and non-steroidal anti-inflammatory drugs (NSAIDS). Morrison and Meier⁵⁹ stated that constipation is common in those requiring palliative care and increases in prevalence with advancing years. Constipation is prevalent in 63% of the elderly in hospitals compared to 22% of the elderly at home and 95% of persons taking opioids.⁵⁹

Assessment of other symptoms using the APCA POS and ESAS scales showed fatigue, Constipation coughing, nausea, headache and diarrhea as described by participants as other symptoms. Tables 4.3 and 4.4. Showed similar results of the assessment of other symptoms. 205 (48.3%) had no other symptoms, 104(24.5%) had mild symptoms of constipation, fatigue, diarrhoea, cough and nausea While 107(25.2%) had moderate other symptoms and 8(1.9%) had severe to overwhelming symptoms.

Fatigue, a common symptom reported in previous study above and also reported in our study by participants, described by patients as feeling worn out, being exhausted, experiencing sleepiness, feeling extremely tired, having low energy and, by care providers, as lethargy or malaise.⁵⁹ Fatigue is often associated with the ageing process and is often difficult to ascertain. The above study described fatigue “as occurring commonly in older adults with end-stage chronic

diseases, advanced disease and combined therapies” which was described by some of the patients with cancer. Some described it as occurring after chemotherapy sessions worsened with nausea and vomiting.

In our study, almost half the number of participants recruited for the study reported moderate to severe tiredness while a quarter described mild tiredness. Participants described tiredness as having some of energy as well as being able to perform some form of movement which is different from fatigue as having no energy. These findings are consistent with the international studies. The results of the psychosocial study show that elderly patients worry about their disease condition, and this can be linked to poor communication either from health professionals or from caregivers. A number of participants reported having little to no advice or help regarding future planning as pertains the goal of care. Worry on the part of the family was also assessed and found to be a problem. This may translate into an increased burden on the family members or caregivers.

5.1.3 Dealing with Psychosocial Needs

Psychosocial dimensions of health among the elderly relate to the changes associated with the ageing process. Harwood et al.⁶⁰ in their 2000 study maintain that psychological conditions- (worry, anxiety, fear, loneliness) can lead to exacerbation of physical symptoms. Worry about the illness was found to be a significant problem amongst the study participants. This is to be expected among the elderly particularly for those who were in active service. Decrease in functions, such as loss of strength, weight loss, low levels of activity or poor endurance, is always a source of worry to the elderly who, manifest these symptoms in subtle or obvious ways. This decline leads to increased hospital attendance, long-term use of medications, fatigue, slowed performance, increased health-related expenses, increased caregiver burden, loneliness and social isolation. The aforementioned are major psychosocial concerns for the elderly. The symptom of worry can also be related to changes in the human body which, some say, can be very frightening or depressing; however, others adapt well.⁶¹

Psychosocial theorists have identified stages of the ageing process. Cynthia B et al⁶² identified the psychological stage of older people in her study where she stated the work of Erikson, an early psychologist, who described the stage of elderly as “the stage pertaining to older adults as ego integrity versus despair”. This stage describes accepting one’s life as meaningful, which potentially helps the acceptance of life and death by older people, helping them see death as a part of life. This observation ties up with the principles of palliative care which states that, “Palliative care affirms life and regards dying as a normal process, and intends neither to hasten nor to unduly postpone death”.⁶³ Addressing psychosocial issues in

the elderly requires a multidisciplinary team approach involving the clinical psychologist, psycho-oncologist, social workers, and physiotherapist, to mention but a few. Poor management of worry and other psychosocial issues may lead to feelings of anger, bitterness, depression, inadequacy, failure and fear of death. It is also important to note an additional source of worry may arise from an inability to function in a parent role or in their loved occupation. Additionally it has been noted that ruminations about a life unlived, where dreams or ambitions have not been achieved, or where the elderly reflect on, past losses (especially those who have lost a spouse or child), or over health problems and health- or age-related physical limitations – all these are of concern.⁶¹ Challenges arising from treatment measures for a disease condition such as cancer can also be a source of worry. Elderly patients receiving chemotherapy can experience distressing symptoms such as nausea, vomiting, even hair loss, which can be a source of worry to them.

In a study carried out by Buzgova et al⁶⁴ on the subject of addressing a palliative care needs assessment in a hospital setting, the authors stated that “the most frequent shortcomings are poor communication, insufficient management of pain and other symptoms, lack of attention given to psychosocial and spiritual aspects of diseases including the problem patients face in coming to terms with their own death”.^{65, 66} It has been found that “[older persons often prioritize other goals such as function, comfort or family support and communication”, which are major aspects of psychosocial issues faced by the elderly.⁴⁹

Palliative care involves identifying, assessing and managing of patients’ needs through symptom control, effective communication with patients and families and respect for patients’ autonomy. Milligan⁶⁶ identified the needs of patients, including those of the elderly, receiving palliative care in hospital as “the assessment and management of pain and other symptoms, including psychosocial and spiritual needs, discussion of prognosis and opinions regarding treatment, identification of the patients’ treatment goals and management of the transition from curative to palliative care.” Other needs identified by Milligan are involvement in decisions concerning resuscitation and other aggressive treatments, psychosocial and spiritual support of patients and their families planning a transfer to another type of facility, and recognition of the signs of impending death”.⁶⁶ This is a comprehensive description of palliative care and provides insight into the breadth of the issues that need to be assessed and addressed in order to meet the needs of elderly patients.

Although not measured in this study, social isolation is a concern for the elderly. For example, the inability to attend and participate in social functions/activities is also a major psychosocial need. The study by Buzgova et al. highlights this fact as it “identified important and unmet causes of psychosocial needs as inability to continue with usual activities, loss of opportunity to attend

religious services or other ceremonies, fatigue, fear of having to depend on the help of others, sharing feelings about death and dying”. The study also highlighted coping with bodily changes, coming to terms with illness, loss of contact with and support from a clergyperson, and sharing fears and concerns”.⁶⁶ Depression was identified during this study as a significant problem. As well as clinical interventions to manage depression, the support for the patient and for family caregivers provided by palliative care can assist in managing depression. Buzgova et al. also stated in their study that “determination of patient’s needs and targeted interventions is an integral part of patient-centered care”.⁶⁷ This study further highlights the importance of palliative care training for health professionals caring for the elderly.

5.1.4 Dealing with Spiritual Needs

Puchalski et al.⁶⁸ defined spirituality as:

“...a dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, nature, and the significant or sacred. Spirituality is expressed through beliefs, values, traditions, and practices.”

Spiritual care is an important aspect of patient care which defines a patient’s meaning to life, hope and source of comfort. It also affects the ability to cope with changes arising from the ageing process or from progression of disease. Palliative care uses a person-centered approach to address these spiritual needs. This research study found that most participants (79.5%) were members of an organised religion as relates their place of worship, 99.3% had God as their help in difficult times, and 79.5% were members of an organised religious group – church, mosque or traditional practices. Despite their ill health and challenges, 97.2% said prayer was an important religious practice to them, serving as a source of hope; 99.8% said there was no conflict between their beliefs and care received, and 99.3% did not have beliefs that affected the care received.

Koenig et al.⁶⁹ describes spiritual care as the heart of what whole-person care encompasses. Their study also showed strong support for recognition that spiritual meaning and purpose (98%) and hope and strength (94%) were spiritual needs. This finding supports the findings of the current study where all participants reported that God was their source of hope. This may be seen as a driving tool for survival even in very distressing health conditions. Being members of an organised religion – that is,

relating to their place of worship, within a faith community which includes prayer as an important religious practice – serves as a source of hope.

The findings from the spiritual assessment showed that the spiritual needs of the elderly surveyed in this study were met. There was also evidence that being a member of an organised religious group served as a means of support for the participants and their family, which, I believe, helped or will help in times of distress from the disease condition and the ageing process. The findings also showed that there were no conflicts between belief and the care being received, or to be received, from the health professionals. This finding is helpful for the health professionals caring for the elderly as the awareness will enhance the acceptability of treatment options given to patients.

In our institution, UCH, a chaplaincy committee has been set up to address the spiritual needs of patients accessing care in the hospital. The chaplaincy committee has a palliative care representative as a member of the committee which is a welcome development for the progress of palliative care within the institution.

The APCA POS showed that a high number of participants felt at peace despite their health conditions. This can be related to the findings from the HOPE assessment tool which showed no limitations in their spiritual beliefs. The strong positive aspect of their spiritual beliefs can be a source for the peace experienced while the care professionals attend to their physical needs.

5.2 Limitation of the Study

The limitation of the study encountered initially was time constraint at the study site.

The study sites were outpatient clinics, allowing questionnaires to be administered only clinic hours which made about 30% of patients reluctant to participate, believing it would affect their appointment. Another limitations of this study is the fact that it is the first research focusing on the palliative care needs of the elderly in Nigeria, which, in turn, led to researching a large number of literature reviews from other countries.

5.3 Conclusion

This study has shown that older people have unmet palliative care needs, with pain being the most significant problem at multiple sites arising from chronic illnesses, especially when there are co-morbidities. Psychological and emotional needs were also identified. These unmet

palliative care needs can be addressed with the extension of palliative care services to the selected clinics and more. Palliative care teams should be involved in conducting clinical consultations, especially in the geriatric unit where most of the participants are recruited from and which is the largest clinic attended by elderly patients. It will also be important to include palliative care in the training of geriatricians so that basic palliative care can be implemented early in an illness to assist patients, and referrals to a palliative care team can be suggested for complex health conditions.

5.4 Recommendation

Palliative care service should be made a priority, and training of health professionals interested in this field should be supported to increase resources required to meet the needs of a growing elderly population. The WHA67.19 on palliative care advises basic level attention (which in our country Nigeria will be at primary/community level), intermediate and specialist levels. The intermediate level would be covered largely at private-owned health institutions in the urban regions as well as at state government hospitals. The specialist levels would be covered at federal government health institutions with their high number of health professionals in the different medical areas.

Palliative Care education would take place through institutional or a country-wide taskforce dedicated to enhancing global awareness and updating curricula to train healthcare professionals in palliative care. This necessity, therefore, calls for urgent integration of palliative care into health institutions in Nigeria and, strategically, through the available geriatrics service in our institution at UCH. However, it must be said that awareness on available palliative care services has been created in the geriatric unit by the palliative care team to enable holistic management of distressing symptoms among the elderly. Furthermore, this also calls for the training of health professionals caring for the elderly in the various clinics.

As a result of this study – being the first of its kind on elderly patients in Nigeria – the APCA POS can be used to audit the quality of care over a period of six to 12 months to see whether there has been a change in the care offered to the elderly. The APCA POS can be used to measure change in items weekly over a four- or six-week period on an annual basis to develop a culture of quality improvement for the implementation of palliative care and response to the needs of elderly patients needs at UCH.

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APPENDICES

APPENDIX 1 INFORMED CONSENT FORM

IRB Research approval number-UI/EC/15/0263

TITLE OF RESEARCH

ASSESSING THE PALLIATIVE CARE NEEDS OF ELDERLY PATIENTS SEEN AT THE UNIVERSITY
COLLEGE HOSPITAL IBADAN

NAME OF RESEARCHER

This study is being conducted by Omoyeni Eunice as the main researcher. Please contact her on 08090722000.

Thank you for giving your time to hear about this research study.

This form aims to explain to you about the study that you may wish to participate in. You are free to ask questions from the researcher, clinical team and you can use the telephone number on this form. Please, take your time to make a decision whether to participate or not in the study. Thank you.

PURPOSE OF THE STUDY

The purpose of this study is to look at the needs of older people and to see how it relates to palliative care, and also to see how access to palliative care services can help improve these needs.

PROCEDURE OF THE RESEARCH

If you agree to take part in the study, we will ask you to sign an informed consent form after adequate explanations have given to you. Then we will ask you to answer questions to obtain information for this research. This will take about 30 minutes of your time.

WHAT IF I DON'T WANT TO TAKE PART IN THE STUDY?

Taking part in this study is totally voluntary. You are free to say No and also free to withdraw if you no longer want to take part in the study. If you choose not to take part or to stop at any time you will still receive the same care in the hospital as you would if you choose to take part and complete the questionnaire. Please take your time to think about it or discuss with your carers /family members or even your doctor.

WHAT HAPPENS IF I AGREE TO TAKE PART IN THE STUDY?

Once you agree to take part in the study, a consent form will be given to you to sign. An experienced researcher will give you a questionnaire to fill (which take between 5 to 10 minutes) and you can ask questions on areas not clear to you. It is a one-time interview. After filling the questionnaire, please, kindly return to the researcher who will wait patiently for you to finish and in case you came to the clinic alone and might need help with your questionnaire. Please feel free to call on the researcher for help.

COST OF PARTICIPATION

Your taking part in the study will not cost you anything or any amount.

BENEFITS OF PARTICIPATION

There are no direct benefits for participating in the study.

RISK OF PARTICIPATION

There are no risk of participation although some questions might cause emotional discomfort. If this occurs, the interviewer will stop and you can choose to withdraw from the study or to restart at a time of your choosing.

CONFIDENTIALITY

All information collected in this study will be confidential. You will not be identified in anyway.

WILL YOU BE INFORMED ABOUT THE RESULTS OF THE STUDY?

A report on the findings from this study will be sent to participants and to the clinic where you were seen.

STATEMENT OF PERSON GIVING CONSENT

1. I confirm that I have read and understand the information on the consent form and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and I am free to withdraw at any time, without giving a reason, without my care being affected.
3. I agree to take part in the above study.

Name _____

Signature _____

Date _____

Name of person witnessing; -----

STATEMENT OF PERSON OBTAINING INFORMED CONSENT

I have fully explained this research to ----- and have given sufficient information, including about risks and benefits, to make informed decision.

Signature _____

Date: _____

Name:-----

CONTACT PERSONS FOR THE STUDY

Please if you have questions about this research, kindly contact the Chairman of the Ethics Committee of the University Of Ibadan, at Biode Building, Room 210,2nd Floor, Institute for Advanced Medical Research and Training ,College of Medicine ,University of Ibadan, E-mail : uiuchrc@yahoo.com and uiuchec@gmail.com

In addition, if you have any questions about your participation in this research in this research, you can contact the principal investigator, DR OMOYENI EUNICE , Hospice & Palliative care unit, UCH. E-mail.omoyenieunice@yahoo.com 08090722000.

APPENDIX 2

DATA COLLECTION TOOL: QUESTIONNAIRE

ASSESSING THE PALLIATIVE CARE NEEDS OF OLDER PATIENTS SEEN AT THE UNIVERSITY COLLEGE HOSPITAL, IBADAN, NIGERIA.

Dear respondent,

Good day to you. My name is Eunice Omoyeni. I am a postgraduate student in the department of Palliative Medicine, Faculty of Public Health and Family medicine, University of Cape Town, South Africa. I am carrying out a study on the above topic. This is a research study and the information you give will be used to improve health intervention for older people. It is voluntary and no name is required.

SECTION A: SOCIO-DEMOGRAPHIC DATA

Study No

QUESTIONS	POSSIBLE RESPONSES
Q1. Age at last birthday (years)	
Q 2. Gender	1 <input type="checkbox"/> Male 2 <input type="checkbox"/> Female
Q 3. Marital status	Single 1 <input type="checkbox"/> 2 <input type="checkbox"/> married <input type="checkbox"/> 3. divorced <input type="checkbox"/> 4 <input type="checkbox"/> widowed 5 <input type="checkbox"/> separated
Q4. Religion	1 <input type="checkbox"/> Christianity 2 <input type="checkbox"/> Islam 3 <input type="checkbox"/> Traditional 4 <input type="checkbox"/> others 5 <input type="checkbox"/> specify
Q5. Ethnicity	1 <input type="checkbox"/> Yoruba 2 <input type="checkbox"/> Igbo 3 <input type="checkbox"/> Hausa 4 <input type="checkbox"/> Others 5 <input type="checkbox"/> specify
Q 6. Level of educational	1 <input type="checkbox"/> none 2 <input type="checkbox"/> primary 3 <input type="checkbox"/> secondary [] university [] others, specify
Q7. Where do you live?	1 <input type="checkbox"/> state 2 <input type="checkbox"/> Town
Q8. Where were you referred from?	1 <input type="checkbox"/> UCH 2 <input type="checkbox"/> private hospital 3 <input type="checkbox"/> self 4 <input type="checkbox"/> others. Specify.....
Q9. Have you heard of palliative care?	1 <input type="checkbox"/> yes 2 <input type="checkbox"/> No , if yes where.....
Q10. What are you being treated for?	

APCA AFRICAN POS

Patient number	Date _____
ASK THE PATIENT	POSSIBLE RESPONSES
Q1. Please rate your pain (from 0 = no pain to 5 = worst/overwhelming pain) during the last 3 days	0 (no pain)- 5 (worst/overwhelming pain) 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/>
Q2. Have any other symptoms (e.g. nausea, coughing or constipation) been affecting how you feel in the last 3 days?	0 (not at all)- 5 (overwhelmingly) 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/>
Q3. Have you been feeling worried about your illness in the past 3 days?	0 (not at all)- 5 (overwhelming worry) 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/>
Q4. Over the past 3 days, have you been able to share how you are feeling with your family or friends?	0 (not at all)- 5 (yes, I've talked freely) 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/>
Q5. Over the past 3 days have you felt that life was worthwhile?	0 (no, not at all)- 5 (yes, all the time) 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/>
Q6. Over the past 3 days, have you felt at peace?	0 (no, not at all)- 5 (Yes, all the time) 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/>
Q7. Have you had enough help and advice for your family to plan for the future?	0 (not at all)- 5 (as much as wanted) 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/>
ASK THE FAMILY CARER	
Q8. How much information have you and your family been given?	0 (none)- 5 (as much as wanted) N/A <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/>
Q9. How confident does the family feel caring for _____?	0 (not at all)- 5 (very confident) N/A <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/>
Q10. Has the family been feeling worried about the Client over the last 3 days?	N/A <input type="checkbox"/> 0 (not at all)- 5 (severe worry) 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> c

**Edmonton Symptom Assessment System:
Numerical Scale**
Regional Palliative Care Program

Please circle the number that best describes:

No pain	0	1	2	3	4	5	6	7	8	9	10	Worst possible pain
Not tired	0	1	2	3	4	5	6	7	8	9	10	Worst possible tiredness
Not nauseated	0	1	2	3	4	5	6	7	8	9	10	Worst possible nausea
Not depressed	0	1	2	3	4	5	6	7	8	9	10	Worst possible depression
Not anxious	0	1	2	3	4	5	6	7	8	9	10	Worst possible anxiety
Not drowsy	0	1	2	3	4	5	6	7	8	9	10	Worst possible drowsiness
Best appetite	0	1	2	3	4	5	6	7	8	9	10	Worst possible appetite
Best feeling of wellbeing	0	1	2	3	4	5	6	7	8	9	10	Worst possible feeling of wellbeing
No shortness of breath	0	1	2	3	4	5	6	7	8	9	10	Worst possible shortness of breath
Other problem	0	1	2	3	4	5	6	7	8	9	10	

Patient's Name _____

Date _____ Time _____

Complete by (*check one*)

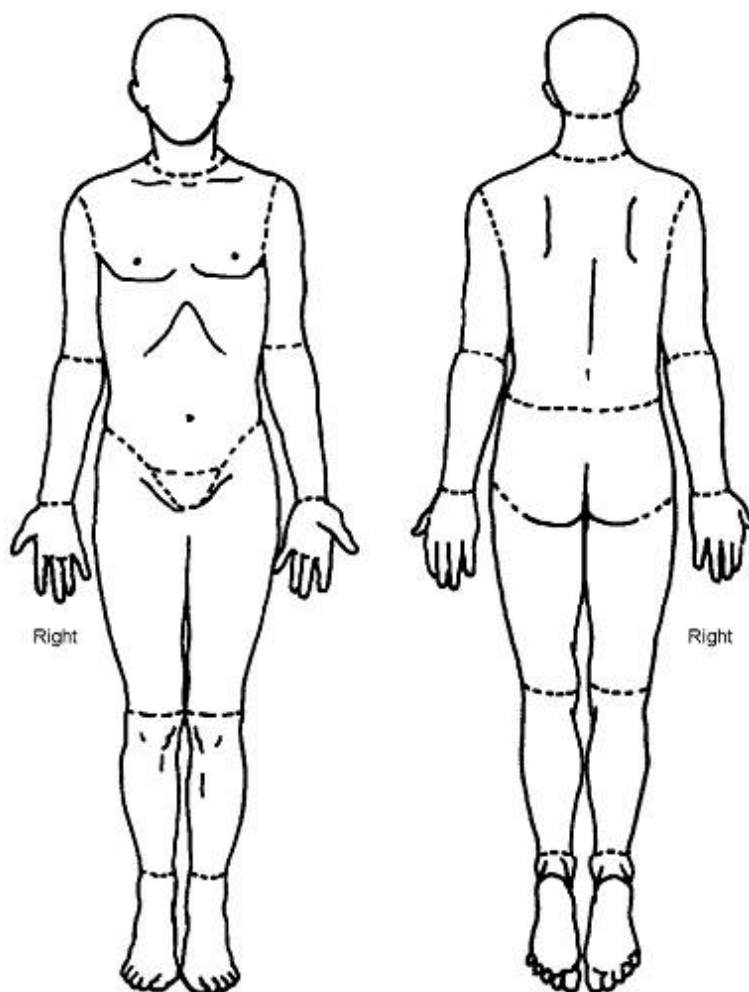
- Patient
- Caregiver
- Caregiver assisted

BODY DIAGRAM ON REVERSE SIDE

(PATIENT'S NAME WILL NOT BE INCLUDED)

The ESAS physical representation

Please mark on this picture where it is you hurt.



SPIRITUAL ASSESSMENT (HOPE ASSESSMENT TOOL)

Table 5.1 HOPE Approach to Spiritual Assessment	
H Spiritual Resources	<p>What are your sources of hope or comfort?</p> <p>What helps you during difficult times?</p>
O Organized Religion	<p>Are you a member of an organized religion?</p> <p>What religious practices are important to you?</p>
P Personal Spirituality	<p>Do you have spiritual beliefs, separate from organized religion?</p> <p>What spiritual practices are most helpful to you?</p>
E Effects on Care	<p>Is there any conflict between your beliefs and the care you will be receiving?</p> <p>Do you hold beliefs or follow practices that you believe may affect your care?</p> <p>Do you wish to consult with a religious or spiritual leader when you are ill or making decisions about your healthcare?</p>
<p><small>Source: Anandarajah, G., & Hight, E. (2000). Spirituality and medical practice: Using the HOPE questions as a practical tool for spiritual assessment. www.aafp.org/.</small></p>	

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UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee



Room E52-24 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6338 • Facsimile [021] 406 6411
Email: shuretta.thomas@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

30 October 2015

HREC REF: 776/2015

Dr L Gwyther
Family Medicine
2.28 Falmouth Building

Dear Dr Gwyther

PROJECT TITLE: ASSESSING THE PALLIATIVE CARE NEEDS OF ELDERLY PATIENTS SEEN AT THE UNIVERSITY COLLEGE HOSPITAL IBADAN NIGERIA (Masters-E Omoyeni)

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study subject to local approval.

Approval is granted for one year until the 30th October 2016.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

Please quote the HREC REF in all your correspondence.

We acknowledge that the student, Eunice Nkechi Omoyeni will also be involved in this study.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Yours sincerely

Signature removed to avoid exposure online

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE

Federal Wide Assurance Number: FWA00001637.

Institutional Review Board (IRB) number: IRB00001938

This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH

HREC 776/2015

2006), based on the **Association of the British Pharmaceutical Industry Guidelines (ABPI), and Declaration of Helsinki (2013) guidelines.**
The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

HREC 776/2015



INSTITUTE FOR ADVANCED MEDICAL RESEARCH AND TRAINING (IAMRAT)
College of Medicine, University of Ibadan, Ibadan, Nigeria.



Director: **Prof. Catherine O. Falade**, MBBS (Ib), M.Sc, FMCP, FWACP
Tel: 0803 326 4593, 0802 360 9151
e-mail: cfalade@comui.edu.ng lillyfunke@yahoo.com

UI/UCH EC Registration Number: **NHREC/05/01/2008a**

NOTICE OF FULL APPROVAL AFTER FULL COMMITTEE REVIEW

Re: Assessing the Palliative Care needs of Elderly Patients seen at the University College Hospital, Ibadan, Nigeria

UI/UCH Ethics Committee assigned number: UI/EC/15/0263

Name of Principal Investigator: **Omoyeni Nkechi Eunice**
Address of Principal Investigator: Hospice and Palliative Care Unit,
University College Hospital, Ibadan

Date of receipt of valid application: 21/08/2015

Date of meeting when final determination on ethical approval was made: N/A

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 **24/11/2015 to 23/11/2016**. 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 expected 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.



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Professor Catherine O. Falade
Director, IAMRAT
Chairperson, UI/UCH Ethics Committee
E-mail: uiuchec@gmail.com



UNIVERSITY COLLEGE HOSPITAL, IBADAN

The pioneer Teaching Hospital in Nigeria.

PM.B. 5116, Ibadan Tel: 0700 824 4357, +234 02 903 1012, +234 02 903 1021 Email: cmd@uch-ibadan.org.ng Website: www.uch-ibadan.org.ng

7th December, 2015.

Dr. Omoyeni, N. E.
Medical Officer,
Department of Hospice & Palliative Care Unit,
University College Hospital,
Ibadan.

Signature removed
09/12/15

Thro' The Head of Unit,
Department of Hospice & Palliative Care Unit,
University College Hospital,
Ibadan.

Dear Dr. Omoyeni,

RE PERMISSION TO CONDUCT RESEARCH

Approval is hereby given to you to conduct the research titled "Assessing the Palliative Care Needs of Elderly Patients seen at the University College Hospital, Ibadan, starting from December, 2015 to end February, 2016.

You are reminded that the confidentiality of the data is paramount in line with research ethics.

Yours faithfully,

Signature removed to avoid exposure online

Dr. L. A. Adebusoye
Director,
CTAGC, UCH, Ibadan.