

**A COMBINED PERCEPTION AND NEEDS ASSESMENT STUDY OF HOME
BASED PALLIATIVE CARE AMONG PATIENTS WITH LIFE -
THREATENING DISEASES ATTENDING THE FEDERAL MEDICAL
CENTRE ABEOKUTA, NIGERA.**

INSTITUTION

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**PROPOSAL SUBMITTED IN PARTIAL FULFILLMENT OF THE PART II
MASTER OF PHILOSOPHY (MPhil) IN PALLIATIVE MEDICINE.**

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DECLARATION

I declare that this study report entitled **“A COMBINED PERCEPTION AND NEEDS ASSESSMENT STUDY OF HOME BASED PALLIATIVE CARE AMONG PATIENTS WITH LIFE THREATENING DISEASES ATTENDING THE FEDERAL MEDICAL CENTRE ABEOKUTA, NIGERA.”** presented for the degree of MPhil .Palliative Medicine at the University of Cape Town is my own personal work and never been presented for any degree or examination at any other University

Signed

Signed by candidate

Signature removed

...

This10 TH..... Day of ...OCTOBER.....2006

ATTESTATIONS

Attestation 1



DR. LIZ GWYTHER. - Date

Attestation 2

David Oliver

- Date 28.4.07

Dr David Oliver BSc, MB BS, FRCGP

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GLOSSARY

- HBC - Home Based Care
- HBPC - Home Based Palliative Care
- HIV/AIDS - Human Immune Virus / Acquired Immuno - Deficiency Syndrome
- PLWHAs - People living with HIV/AIDS
- TIP - Terminally ill - patients.
- HAART - Highly Active Anti – Retroviral Therapy
- WHO - World Health Organisation

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1.1 ABSTRACT

This study aimed to evaluate the perception and needs for Home Based Palliative Care (HBPC) among patients suffering from life-threatening conditions presenting at the Federal Medical Centre Abeokuta, Ogun State, Nigeria. Needs assessment for this specialized care were investigated among cancer and HIV/AIDS patients receiving treatment in this health institution. Questionnaires were administered to the patients and statistical analysis of the collected data evaluated.

Ethical approvals were obtained from the Hospital Ethical Review Committee of the Federal Medical Centre Abeokuta, Nigeria and the Ethical Review Committee of the University Of Cape Town, South Africa.

This research has provided recommendation that may assist in providing HBPC and improve the quality of life and care for such patients requiring palliative care in Abeokuta, Ogun State, Nigeria and its catchments area.

The results show that:

1) The level of awareness of Home Based Palliative Care (HBPC) is low among the patients under study in the Centre and possibly in other part of the country. It was quite obvious from the respondents that there is no standing or known HBPC program in the country. Some reasons likely to be responsible for these findings were further discussed and some recommendations made in the light of these revelations.

2) The respondents received HBPC information with lots of enthusiasm and were all eager to embrace this model of care. They emphasize the needs and its relevance in their response to the open-ended questions and also offered their opinions on the services based on their limited knowledge of HBPC.

CHAPTER 1

INTRODUCTION

1.1 General

According to the World Health Organisation (WHO), Palliative Care is defined 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].

This study was designed out of a concern for the end of life experience of patients diagnosed with life threatening illness at the Federal Medical Centre, Abeokuta Nigeria.

Curative medicine often takes the stand that there is nothing more we can do and in effects abandon patients to the care of their families who are not equipped to provide the needed care. Palliative care is a field of medicine that developed to combat the effect of this negative approach on both the patients and their families.

There is a significant number of patients with life – threatening conditions that present very late to the hospital at an advanced stage of illness. [2] The late presentation may be associated with the limited access to health facilities, which is a common problem in other African countries including Nigeria where most patients lack access to health care [3]

Often at the time of presentation the patients' condition is so far advanced that they are unable to benefit from acute care but rather require End of Life care. The End of Life care goal is to achieve the best quality of life for both the patients and their families making them comfortable and promote dignity in dying.

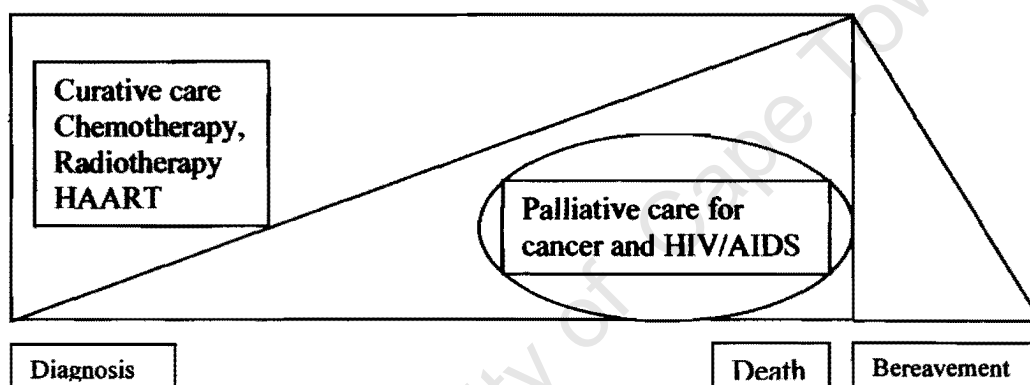
Generally, the health care system in Nigeria is a pay for service arrangement and access is even more difficult for patients suffering from life-threatening conditions requiring expensive treatment which may be unaffordable. There are no special budgets or privileges to cater or cushion their health spending nor is there any National Health Insurance Scheme (NHIS) provision. The national health budget has always been insufficient for curative care services posing a big challenge for funding end-of-life care. End-of-Life care does not receive sufficient attention in the hospitals, considering the fact that palliative care is a new concept in the country.

In the past, the sick and the elderly were cared for by family members and neighbours. They would come around to visit the sick and ask of their needs, cook, wash their clothes, talk to them, keep them company and offer the needed helping hands where necessary. However, there is erosion of the traditional extended family system and communal life in Nigeria in recent times

The challenges of life impact negatively on the society and sometimes an informed child of the sick working in urban area may not respond or return to village to care for the sick parents or may only return to the home after the patient has died. Our traditional culture of being a care for each other actually supports Home Care and is worthy of

Home Based Palliative Care model may be a viable option for patients suffering from advanced disease conditions whenever the hospitals believe 'there is nothing more we can do'. Although the home-based care concept is virtually unknown in the Nigeria, it had recorded laudable successes in Kerala India, with the Integrated Community Hospice Care in South Africa by the Hospice and Palliative Care Association of South Africa and Hospice Uganda in East Africa.

Scope of Palliative Care in advanced disease



Source: Adapted from World Health Organisation Cancer Pain Relief and Palliative Care. Technical report No. 804 Geneva, WHO, 1990 [4, 5]

The graph shows how palliative care is appropriate alongside disease – specific care and becomes more important as the disease progress.

Home Based Palliative Care (HBPC) is regarded as a model of care that provides the above services to the patient and family at home. The term Home Based Palliative Care (HBPC) involves providing physical, psychosocial and spiritual care for terminally ill people including their family members at home. The World Health Organization (WHO) defines home care as “the provision of health services by formal and informal caregivers in the home. Such care includes physical, psychosocial, palliative and spiritual activities”, WHO further states that the main goal of home care is “is to provide hope through high quality and appropriate care that helps ill people and families to maintain their independence and achieve the best possible quality of life” [1, 6].

Home –based Palliative care adds to the Home Based Care (HBC) concept in providing prevention and relief of suffering including:

- Provides relief from pain and other distressing symptoms
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patient’s illness and in their bereavement;

Home Based Palliative Care (HBPC) is therefore the provision of Palliative care at home for both the patients and their families in their homes with the aim of improving their quality of life, dignity in death and support in bereavement.

Who are the patients requiring palliative care?

These are the chronically ill or advanced disease patients that may no longer respond to curative options and subsequently require end of life care. These categories of patients include advanced cancer stage, people living with HIV/AIDS (stages III and IV), end stage cardiovascular, respiratory, metabolic, respiratory, hepatic, renal and progressive neurological disorders. For the sake of this study, cancer and HIV/AIDS patients in these two stages were the target group.

1.2 RATIONALE OF THE STUDY

Barriers to palliative care within the Hospital settings

a) Financial Resources:

Health care delivery in Nigeria is mainly self - financing and may be unaffordable or not easily accessible to most patients. The country's low socio-economic conditions with inadequate National Health budget that usually oscillate between 2-5%, makes provision of good health care delivery difficult. The total expenditure on health as percentage of Gross Domestic Product (GDP) in 2002 was 4.7% [7] while the over all per capital GDP was just \$114,685million in 2006. While in UK the GDP was \$2,375trillion in 2006. [8] Patients suffering from life-threatening illnesses especially advanced cancer patients have to compete unfavorably for the available limited health facilities and resources with other acutely ill patients. Hospitals in the Nigeria operate on a pay-for-service basis for those that can afford it while HBPC may offer an alternative cheaper cost of care besides other

Comparative analysis of GDP between Nigeria and UK

Country	GDP (\$)	Per capita (\$)
UK	\$2,375 trillion	\$38,624
Nigeria	\$114.69 million	\$ 1,188

b) Patients:

Most Patients present very late in advance stage of their illness and requiring best quality of care which can only be offered at the tertiary health institutions with good facilities and highly skilled personnel. The national health reforms put in place by the Federal Government of Nigeria mandated Commercialization and Autonomization of the health sector making the services more expensive and unaffordable to an average person. The patients at this stage of their illness are not able to work and do not have an income and unable to meet up with the hospital bills. HIV/AIDS and cancer patients also experience denial, social and self stigmatization which often makes them shy away from hospital care as soon as the diagnosis is made. Some will prefer to consult the Herbalist or Spiritualist with belief that the disease is as a result of witchcraft.

c) Health Care Workers

Health Care providers at the Federal Medical Centre, Abeokuta, Nigeria and in other Centers in the country do not offer much attention to advanced cancer patients especially those health care workers that have not received Palliative care training. They do not have the knowledge and skills and therefore are not confident in providing End-of-Life care. Some are afraid of the risk of being infected with HIV in the course of their duty and discriminate against HIV/AIDS patients. Palliative care is just developing across the country and the health care providers have limited or lack adequate skills and knowledge to provide holistic palliative care.

Palliative care Needs

It is estimated that more than 0.5million cancer deaths are being recorded annually in Nigeria [9] and the rates are expected to grow by 400% over the next 50years [10]. About 80% of Cancer patients in developing countries present to the hospital for the first time at an advanced and incurable state. Coupled with this is the fact that there are in 2006 there was an estimated 2.9 million Nigerians currently infected with HIV a figure only surpassed by both India and South Africa respectively [11]. HIV/AIDS is a social problem requiring palliative care to improve the quality of life of both the patients and family and in some cases may be complicated by other HIV related Cancers like Non Hodgkin Lymphoma, Cervical Carcinoma and Kaposi's Sarcoma.

In 2005 alone, about 300,000 adults were newly infected with HIV while 4.4% of women attending Ante - Natal Clinic (ANC) were found to be infected although the prevalence is more than 5% in about a dozen of states in the federation but the prevalence is higher in rural areas [12].

Is there a need for Palliative Care in Nigeria? This can be evaluated from the number of deaths from cancer and HIV/AIDS where Palliative care services may make a positive impact. The Palliative Care burden or needs of a community can be estimated from the "Cancer and HIV/AIDS deaths plus a 2% deaths from other chronic life threatening conditions" [13]

The 1996 national census confirmed that the population of Nigeria is about 140 million inhabitants and with the increasing number of patients suffering from life threatening conditions, the limited health facilities and resources pose a challenge. The challenges confronting them are numerous even when they are able to access the hospital facilities. These may include huge costs of hospital bill, loneliness, and lack of privacy, confidentiality and lack of compassion which often frustrate and make the patients shy away from prolonged hospitalization and prefer to be home.

Considering these dilemmas and the limiting factors in the hospital system, Home Based Palliative Care (HBPC) may be a reasonable alternative with its reduced cost and convenience to both the patients and their family.

1.3 Home Based Care (HBC)

Home-based Care has evolved over several decades worldwide as an alternative to hospital based management for advanced disease patients. An improved general health, vitality, emotional and social function have been documented as proof of a better quality of life in this model of care. Home Based Care is a recognized integral part of Palliative medicine and has evolved as a very invaluable outreach care and a feasible alternative approach to the management of these patients. The concept is to reduce hospital admission and encourage patient's care and dying at home with the privilege of being surrounded by their loved ones. Patient and family satisfaction is a very valuable indicator in measuring the quality of care in a home based care setting. This philosophy of care as an integral part of Palliative Care Services is well established not only in developed world but also in some part of Africa like East and Southern Africa [14, 15].

Home Based Palliative Care

Home Based Palliative Care (HBPC) is more comprehensive and holistic in nature compare to Home Based Care (HBC) as it caters for the physical, psychosocial and spiritual well-being of the patient in a more convenient way compared with the hospital settings. The basic clinical care components of palliative care like pain and symptom management can also be effectively provided at home. The HIV/AIDS opportunistic infections and cancer complications may be referred to the hospital for appropriate management if necessary.

Patients are often dissatisfied with prolonged admission, inadequate empathy from the hospital staff, rigid, hospital time table, accumulated financial cost, the stereotyped hospital meals and the lack of privacy [16]. The hospital settings when compared to homes are impersonal and respond only to patients' clinical needs and several works and studies on HBC revealed that most patients prefer to die at home peacefully with their families rather than in the hospital, this may be one of the reason while patients in other parts of the world prefer home based care at their end stage of life [17, 18].

Research has shown that most advanced disease patients do prefer to die at home [19] but it has also been observed that there is no established formal Home care for these patients in Nigeria and they are usually taken care of by the family members. However, in the recent time the families prefer the patients to stay in the hospital in their last days considering the challenges of managing the patients at home with out the assistance of the health care professionals.

The Home Based Care practice being provided by the Community Health and Primary Care department of this hospital is currently not holistic in nature as it lacks pain control and other supportive care. It is more or less a Home visit follow – up of default patients does not reflect an interdisciplinary concept expected of home based palliative care. A need assessment of HBPC in the hospital is therefore necessary to improve upon the present level of HBC practice.

HBPC is a family centered care aimed at improving the quality of life of the patients and families. It is indeed another convenient way of providing end of life care to terminally ill – patients and could be regarded as “Care for the patient within his or her community (domain) involving the family members and other care givers” home - based care therefore provides a comprehensive service to the patients; it promotes, restores and maintains their maximal level of comfort, function and health in a more conducive setting. The improved quality of life, lower costs, reduced pressure on hospital facilities and other various advantages to both the patients and the family are enough incentives that should motivate the introduction of HBPC model of care to Nigerians [20].

Its uniqueness lies in the multidisciplinary team approach. The team members are usually experts in their various areas of callings, they share responsibilities, exchange views, information, and support system and spend more useful time with the patients and family compared to that in the hospitals.

The huge benefits as documented in several literatures include reduced costs, privacy, joint care planning, familiar environment, easing pressure on available limited health facilities and freedom of sexuality; stigma reduction can not be over emphasized as the resultant outcome ensures improved quality of life for the patients and family. [20,21].

This model of care is not well established in Nigeria but there is no doubt that it could be introduced to the patients' advantage. The home care model may be a little challenging to practice as the national health care policy has not prioritize taking health services to patients homes. Government owned hospital do not pay any significant attention to Palliative Care services until few years ago and the government has not formally recognize nor integrate Palliative care practice into the National health policy as prescribed by the World Health Organization (WHO).

It is only the NGOs, Faith Based Organization and some personal efforts of individuals in three Tertiary Health institutions including Federal Medical Centre, Abeokuta, Nigeria that have shown interests in developing this service. HBPC needs assessment survey among a cross section of patients suffering from patients with life threatening illness in Nigeria may be a good pointer to the patients' expectation and this research work is to evaluate its relevance among the target group.

This study is therefore designed to evaluate the needs, perception and relevance of HBPC in a typical Nigeria setting. It is expected to sensitize and create awareness among the patients and the final outcome may justify the feasibility of adapting this model of care in Nigeria. It was also aimed to explore the feasibility and acceptance of Home Based Palliative Care with the overall goal of improving the quality of care of such patients in Nigeria. It is hoped to serve as a resource or baseline for HBPC development in the country either by an individual or even the health policy makers in the future.

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CHAPTER TWO

2.1 REVIEW OF RELATED STUDIES

LITERATURE REVIEW

Literature search was initiated using several search engines including HINARI, Endnote X, and Pub Med, to identify several journals on the Internet and hand search of Palliative Care and Medicine library text books. There is no literature on Home Based Palliative Care (HBPC) in Nigeria since the specialty is still at early stage in the country and most health care providers are not even aware of Palliative Care or a formal end of life care at home. [22, 23]

Home based palliative care (HBPC) is holistic in nature compare to home based care (HBC) as it caters for the physical, psychosocial and spiritual well-being of the patient in a more convenient way compared with the hospital settings besides providing pain and symptom control.

This chapter will focus on the importance of integrating palliative care into HBC which is already in existence in the country. It will trace the historical development of home-based palliative care and look at some successful international models of HBPC, including HBPC for children and also for illnesses other than cancer and HIV/AIDS. The chapter also looks at the level of awareness of HBPC, challenges to providing HBPC and the costs compared to hospital based palliative care currently being practiced at the Federal Medical Centre, Abeokuta Nigeria

There are some International studies on Home Based Care (HBC) rather than on HBPC awareness and needs assessment from the patients point of view, however, some works reviewing the performance of the existing HBC in some African countries including Uganda were identified [24,25,26].

A number of publications explore the needs for home care and acknowledge its convenience and reduced costs to patients among other gains [27, 28], which includes easing pressures on the limited health facilities. The primary goals of this model of care is to empower the patients and motivate a strong bond or relationship with their loved ones, reduced the stress of care at home and for the patient to die peacefully in the comfort of their homes in the presence of their loved ones. It is a compassionate and patient-centred approach with an added advantage of empowering the families to conveniently cater for the patient at home and it is regarded as an invaluable integral component of Palliative Care [29, 30]. Ahiner –Elmqvist and his colleagues in their study concluded that “death at home was associated with patient living together at home with someone and this had really empowered the patients to die in the place they desire”. [31]

REVIEW OF HOME BASED PRACTICES

There is dearth of published work on HBPC in Nigeria as literature search did not reveal any previous work but there are some on HBC. It is worthy of note that the difference between a home based care and home based palliative care is the holistic approach and pain management of the latter model of care.

Soyinka in his study evaluated the needs assessment of HBC among Nigerian HIV/AIDS patients and concluded that Home Based Care can be ideal in uncomplicated People Living with HIV/AIDS (PLWHAs) who did not have clinical complications [32].

This actually motivated my interest in this study considering the prevailing lack of home based palliative care services in the country.

There is always a palliative care need for any community but its relevance or needs in countries especially in Nigeria ought to be evaluated. HBPC is a health need of terminally ill patients in any society and a recognised cardinal component of palliative care services targeting advanced disease patients at home. Some of the advantages include patients' quick adjustment to the comfort of their homes and the sacrifices of the health care professional to manage them at home as an alternative to hospital care [33, 34].

Cummings discusses "the multi-disciplinary team approach at home with the participation of various health care professionals as a privilege which may not even be available in some health institutions". It offers the patients an opportunity to be closer to their loved ones, a better privacy, security and patient autonomy is more guaranteed as there is always a partnership in Care plan between the patient and family for its successful implementation [35].

The health care providers are able to see first hand the patients and their family at home and supervise their medication, have a family meeting, can understand the patient better and plan the management together. Whereas in the hospital the patient's relative may not be allowed stay with the patient, the services are often times paternalistic, a stereotyped lifestyle including feeding, burdensome patient monitoring and costly expenses [16].

Historical Perspective

Home Care began in US around 1885[36] in an era when seriously ill patients were cared for in their homes and home was regarded as the nurse's workplace. The first Hospice in US was established in 1974 while the modern day Hospices and home care in UK was championed by late Dame Cicely in the 1967 [37]. In Nigeria and United States, Palliative Care was never embraced until the scourge of HIV/AIDS, it is the recognition of incurable illness that prompted the need to do something and offer some care (palliation) to the patients [38]. Although the introduction of Highly Active Anti-Retroviral Therapy (HAART) has impacted positively on HIV medicine transforming an earlier deadly disease to a more manageable chronic disease but some of the patients still die of AIDS related complications requiring palliative care.

Struthers [39], in his paper "No place like home" extensively studied home care practice in Ontario as far back as post World War II. According to him the debate on the home versus institutional care had been on since 1940 and at present the home based care approach is still being applauded as most Americans especially the older ones prefer to die at home [40, 41].

In Nigeria HBPC is relatively new, Fatunmbi a retired Nurse after visiting the famous St. Christopher's Hospice in UK sometimes in 1993 decided to establish a private Home for terminally ill patients in Lagos which later transformed to Hospice Nigeria. This was the first hospice in the country to provide home care for referred Palliative Care cases and the patients were coming with their morphine from abroad [42].

There is need for this model of care considering the challenges the patients undergo shortly after their discharge from the hospital. They may lack the needed assistance from family members and experience stigmatization from other close associates, the latter may abscond for fear of being infected by HIV/AIDS. The patients may be frustrated into a life of isolation compounded by neglect and lack of personal resources [43]. Nacwe confirmed that HIV/AIDS epidemic is a "burden on Public health facility in developing countries due to limited resources, Home Based Care services is expected to shift the burden of care to families and communities as public health services are often stretched beyond capacities" [44].

Review of different types of Home based Care in some countries:

1. A Team managed Home based Care (TM/HBPC)

This model was assessed by Jody Oesterreicher et al, whose sole aim was to improve the quality of life for Veteran patients in US. The patient's functional status, their quality of life together with that of their care giver, hospital re-admission and costs of care were evaluated and found to be encouraging [45].

A significant improvement in their emotional, social, vitality, mental and general health was noticed. Compare to the other Medicare home programs, it was found that the health care team was able to exercise a better clinical judgment at this setting, they do not require a separate salary and they were able to sacrifice some of their time for the program.

Studies of some home care services in some African countries like South Africa, Malawi and Eastern Africa highlighted significant successes and benefits in those countries that are worthy of emulation as most countries in Africa share some cultural semblance.

2. Integrated Community Based Home Care (ICHHC)

South Africa

The South Africans identified the need to develop community support for terminally ill and their family by instituting “Integrated Community based Home Care (ICHHC)” model. A pilot study was conducted in KwaZulu Natal in 1998 and the initiative has led to a significant evolution of Home – Based institutions across the country. [46] [47]. Nacwe noticed a more positive attitudes towards HIV, better knowledge of HIV and reduction of Sexually Transmitted Infection among HIV/AIDS patients in the program besides other positive benefits[44]. It was also noticed that 57% of patients in this setting actually died at home [48].

Malawi

The Bangwe project in Malawi is a joint home based care (HBC) project run by the Salvation Army and the Department of Community Health, College of Medicine, University of Malawi. The project was designed to provide HBC services against the background of limited health facilities and the preferences of terminally ill patients to receive care and die at home [49].

East Africa

Home Based Care is well entrenched in some East African countries like Kenya and Uganda.

A considerable and commendable achievement has been achieved all over Uganda as there are various organization actively involved in the provision of Home Based Care for the citizenry. These include Hospice Uganda, TASO and MILD MAY International community out reach programme. Specially trained Nurses have been empowered to prescribe and administer opioids in the community to relief pains and other needed services at home in situation whereby there is shortage of doctors [50].

India Experience

Kumar in their Palliative home care experience successfully empowered both the patients and their families to provide care at home. They were also able to offer symptom control, emotional support, home visits, some minor procedures like wound dressing, nasogastric intubation, intravenous fluid therapy, bladder catheterization.

Other gains include change of families' attitudes towards the patients. It was concluded that palliative home care was feasible and essential in India. [51]

The Motala Swedish hospital - based home care model was established in 1977 as the first of its kind in Sweden with the family members as the primary care givers. The model aims to replace hospital care for patients in need of institutional care [52]. Beck-Friss research also describes a lower cost of home care than that of any hospital care. Patients' families and relatives take on the role as carers at home which contributed to lowering costs.

The availability of a Nurse or Doctor anytime of the day with immediate guaranteed hospital bed if needed was a suitable, feasible alternative and a replacement to hospital care [53]. The research showed that as many as 89% of those patients that wish to be at home until death in this study actually achieved this although an emphasis was placed on the need for both the family and patients approval. Accessibility of Palliative Care to patients with its cheaper costs and the appreciable sense of security being at home by the patients and carers make it acceptable [54].

To the patients, this is a more convenient and affordable model of care but to the health care providers and the family supporters it may be an added burden. The interdisciplinary team has to visit the homes while the families need to make sacrifices and extra efforts to care for the patient at home. Sanz-Ortiz J et al in their studies found out that Home Care increases the percentage of terminally ill people dying at home with their symptoms are

adequately alleviated, good communication and family support are provided [55]. This finding also corroborated another study by Tang which showed that terminally ill patients with cancer acknowledged dying at their preferred place of death as highly important [56]

Sorbye reported a study of fifteen patients at the end of life who chose to leave hospital based care because of their negative experiences in hospital to receive good palliative care at home. Only a third of them were re-admitted to hospital at the final days of their life indicating that about two-thirds did well and died at home. [57, 30] By this arrangement, the hospital beds are freed and those patients that were supposed to be bed blockers stayed at home at a lower cost.[58, 59], this was further corroborated by the studies of Higginson and McCarthy that home is the preferred site of care by both the patients and the family[60].

The primary goal of HBPC is to support people to die in the comfort of their own homes. Home Based Palliative Care (HBPC) is not only rewarding and applicable to the adults and geriatrics but also suitable for the terminally ill children.

Home Based Care for Children

Duffy in his work studied 34 children suffering from Central nervous system malignancies and about 68% of them in the study died at home. This study confirmed that prolonged hospitalization for children suffering from terminal illness can be avoided by offering them a home based programme.

Most of the problems were adequately managed by the parents under the supervision of the team and 80% of the patients were provided for at home.[61] Berrien in their study on HIV positive children and their families found out that home care ensured a better adherence of prescribed medication regimens.[62]

The Physicians, Patients and the family of the patients have come to accept this model of care as excellent alternative to hospital care and always affirm their support and encouragement [63] [64] but not without the needed technical and emotional support as required by the patients and families. [65].

Collins work also showed that there was a greater freedom, more privacy and less disruption to family life, and that caring for the child was a positive experience for most families [66] The sole aim of Home Based Care is to improve the quality of care of the patients and the benchmark of this includes good symptom control such as pain. Mercadante in his study was able to confirm that managed home care system enables patients to receive adequate pain management according to the WHO guidelines even in the comfort of their homes. [67]

Home Based Care for Non-malignant diseases

It has also been reported as a realistic alternative for the bed blocking chronically - ill patients like Stroke patients. While the study done by Widen et al went further to confirm the possible rehabilitation of stroke patients at home as a feasible, possibly less expensive

alternative and complement to current rehabilitation in the hospital [68]. Enguidanos in his work strengthen the fact that Home based Palliative care could be extended to other disease like congestive heart failure, chronic obstructive pulmonary disease and cancer at a significant saving cost and more importantly increasing the likelihood of dying at home of such patients[69].

Huang also observed diabetic control of elderly people with Diabetes mellitus living alone. Suffice to say that chronic diseases like stroke, renal failure and diabetes mellitus can be offered home based care. [70]

Challenges of Home Based Care

HBC is undoubtedly a very challenging model of care even in developed world where all the structures appear to be available and this includes the needed skill and training for the health care providers and the caregivers. [71] It is a multidisciplinary approach involving Medical, Nursing, Social workers, Physiotherapist, Spiritual personnel and as such there must be adequate provision for these interdisciplinary manpower.

The other challenges of home based care for patients with life threatening illness are lack of immediate access to appropriate medical health services, lack of durable medical equipment, financial problem, lack of government support housing problem and lack of proper health education for family members [72,73]. Uys' study on the cost of Home – Based among terminally ill patients in South Africa showed that “Home - based care costs are increased in rural areas where a vehicle is required for staff transport” [74]

According to Ajisaka, patients suffering from terminal conditions always seek the following requirements - to impart on to the caregiver or family members a technical skill and knowledge of nursing care, prompt consultation with the health care workers anytime of need by both the patients and family with adequate support.[75] Thoren compared those patients that died at the hospice and at home and found out that there was no significant difference but rather the psychosocial preparation determined those patients that will die at home. He emphasized that psychological support for family members, access to hospital bed when needed including patient and family consent determine the success of home care. [76]

Comparative costs of Hospital care and HBC

Witteren, showed that a significant savings can be obtained by implementing home based program that involves transferring Palliative Care technologies to the home setting.[77].McCusker and Stoddard in their study observed a greater cost savings for Home based care users in terms of reduction in hospital days and by a reduction in mean daily cost of hospitalization [78].This finding is similar to that of Brumley who concluded that multidisciplinary approach “provides a cost effective method in the provision of home-care services for terminally ill AIDS patients” when compared to the traditional treatment approach [79]

One of the challenges of caring for patients with life - threatening conditions in Nigeria is that of funding as most of these patients are indigents with nobody to assist them. The prevailing economic condition faced by these patients in Nigeria is not encouraging and

calls for government intervention. Adebayo and his colleagues in their study on some patients suffering from life-threatening diseases at Ile-Ife in Nigeria “recognized community – home based care activities as a veritable need but there is little information on them in Nigeria” [80]. Previous studies on Palliative Care and Home Based Care in Nigeria only explored the low level of awareness among the health care providers and not the patients [22, 23].

Rationale of the study

This study is aimed at evaluating the needs, perception and relevance of HBPC in a typical Nigeria setting among a cross section of patients suffering from life threatening conditions. It is expected to sensitize and create awareness of HBPC among the patients in a country where palliative care is almost non-existent. It was also aimed to explore from the patients their perception of the best way to improve the quality of care of such patients in Nigeria.

Previous works and studies on HBPC in other part of the world as revealed by the literature reviews documented its various benefits but its feasibility here in Nigeria needs to be explored.

The final outcome may justify the adequacy of current care for this target group of patients or the need for adapting this new model of care in Nigeria. It is hoped that the study will serve as a resource or baseline for HBPC development in the country either by an individual or even the health policy makers in the future.

CHAPTER THREE

AIM AND OBJECTIVES

3.1 Aim of the study

To assess the level of awareness of home-based palliative care and establish the needs acceptance of Home Based Palliative Care among Patients suffering from life threatening conditions attending the Federal Medical Centre Abeokuta, Nigeria.

3.2 Specific objectives

- To identify the level of awareness of HBPC among the target patients.
- To identify Perception of HBPC among the patients.
- To sensitize the patients to the availability of this model of care.
- To explore Home Based Palliative Care (HBPC) as an alternative model of care for advanced disease patients.
- To evaluate the needs of the patients required to receive quality care in a home based setting.

METHODOLOGY

3.3 Study design

This is a descriptive cross-sectional study conducted by structured interview of patients guided by a questionnaire (appendices) was used. It was designed and finalized for use after several discussions with both the supervisor and the research assistants.

The tool (questionnaire) was used to evaluate the demographic characteristics, respondent information and measures the subject level of awareness of HBPC, perceived needs, opinions and preferences of the respondents. A pilot study was conducted among five (5) patients to validate and test the applicability of the questionnaire and both the faults and defaults were identified and appropriate adjustment made.

The validated questionnaires were administered on the patients that met the eligibility criteria as highlighted below. The questionnaire was administered in the patient's native mother language regardless of his or her literacy level by the research assistants (Medical officers and Nurses) who are members of the Hospital Palliative Care services.

These assistants were already trained in research ethics and on how to administer the questionnaire by the research scientists. The target group included the in-patients who were diagnosed with life-threatening illness and those attending the out-patients departments of the hospital.

3.4 Study site

The study was conducted at the Federal Medical Centre Abeokuta, Ogun- State .Nigeria

3.5 POPULATION

The study population consisted of adult patients diagnosed with life - threatening conditions attending the health institution. The study was conducted among the in and out patients at the Centre. All the identified patients that fall into the inclusion criteria described below were recruited for the study over a period of three months (June – August 2006) in a sequential manner as they come into the hospital service.

3.5.1 Selection criteria

Inclusion Criteria

Adult patients diagnosed as suffering from life-threatening conditions like HIV/AIDS and cancer. Cancer patients including those with metastases already diagnosed as incurable.

HIV/AIDS patients WHO clinical stage 3 & 4 with CD4 count < 200 cells/mm³ attending hospital ARV clinic

Exclusion criteria

Patients that appeared too frail, acutely ill, confused and imminently dying.

Patients that are below the age of 18 years.

3.5.2 Sampling.

All the eligible patients based on the above named criteria were approached to take part in the study. It was by Purposive sampling of all patients with diagnosis of life threatening illness, recruited through process of informed consent. Patients were invited and recruited to participate in the research from the pool of HIV/AIDS and cancer patients attending both the HIV/AIDS and Oncology out – patient clinics and also from the in – patients. Most HIV/AIDS patients were recruited from the newly established Anti – Retroviral (ARV) clinic while the Cancer cases were recruited among referred patients to the Hospital Palliative Care Team and from the oncology clinic

3.6 Data collection

3.6.1 Data Collection tool

Efforts were made to identify adaptable tools from search engines using a systematic search in HINARI but most of the tools focused on the needs assessment at Home Based Care rather than on the needs assessment for HBPC. The Research Instrument was developed from the identified literature reviews on Home Based Care, information inputs, informal interviews and interactions with patients suffering from life-threatening conditions attending the hospital.

These included HBPC awareness, its feasibility and need at home and awareness of any known HBPC organization. Patients' assessment of hospital care was explored on Likert scale. Other issues considered were the psychosocial and spiritual concerns and their preference to stay at home.

The tool explored the demographic characteristics of the subjects, specifically targeted two issues and required the respondents to give information about their level of perception of HBPC and its needs assessment.

VALIDITY AND RELIABILITY

The questionnaire tool was designed from the identified available scientific resources, interviewing of the patients, the researcher's personal experience and discussion with research supervisor and items like Information needs, physical needs, support needs, spiritual needs and psychosocial needs of the patients were identified. [26] The questionnaire was reviewed by two members of the Centre's Palliative Care team for its evaluation and constructive criticism. The essence was to allow neutral persons evaluate the method used in designing the instrument and the sensitivity or appropriateness of the instrument. A pilot study was done and five patients were tested with the questionnaire prior to the study to confirm the reliability of the instrument. Its validity was also explored to denote the consistency of the items by pre-testing. The suggested outcomes were later incorporated into questionnaire and re-tested again after the changes before the final draft is designed to ensure its validity.

3.6.2 Data Collection Method

The Medical officers and Nurses recruited into the study are members of the hospital palliative care team. They received training in Research ethics in palliative care attitude including sensitivity to patients concerns and the administration of the data collection tool prior to the commencement of the study.

The participants were assured to receive all the usual care as required in the hospital without any form of discrimination even if they decide to opt out of the study.

There was no coercion or perverse incentive to the patients and they were free to choose whether or not they wish to participate and also free to discontinue their participation in the course of the interview at any time. The study was fully explained to the patient using the Patient Information (appendix) sheet with both verbal and written consent obtained before administering the questionnaire by interviewing.

The questionnaires were administered to the respondents by the research assistants which were Resident Doctors, Medical Officers and Nurses working in the Centre. They were able to assist those patients who were unable to personally fill the questionnaire because of their literacy level by filling it on their behalf although the questions were presented to them in their respective mother's tongue. The data security was taken care of by the Research Scientist who collates and keeps the information at the Palliative medicine unit of the hospital through out the study period.

3.6.3 Data Analysis

1. Statistical Package for Social Sciences (SPSS) software was used to compute and analyzed the data after collation. A basic descriptive statistical analysis was used to process the data. Frequency counts, percentage, mean, mode and standard deviation of the data were explored.

2. **Thematic analysis – a qualitative analysis of the open – ended comments by the respondents using different themes. The themes were grouped together, coded and analysed separately**

3.7 Ethical considerations

Approval for the study was received from the Hospital Ethical Review Committees (ERC) of the Federal Medical Centre Abeokuta, Nigeria (copy attached) and the ERC of the University of Cape Town (UCT) Cape Town, South Africa.

ETHICAL CONSIDERATIONS WITH REGARD TO RESEARCH AND PALLIATIVE CARE

Patients suffering from life-threatening diseases are prone to be psychologically disturbed and need to be approached with sensitivity. The patients in this study were less affected by these issues as most of the patients had been earlier recruited to the hospital palliative care services. The rapport already established together with the confidence previously built by the patients in the health care providers makes it easy to discuss very sensitive issues with them in form of counseling.

Bearing in mind that palliative care patients are vulnerable the previous confidence the patients have in the institution provided a platform that form that eliminated any form of coercion or given incentives to the recruitment of the participants for this study. Some of the patients are receiving their Highly Active Anti-Retroviral Drugs (HAART) free of

charge in the hospital while some of the cancer patients attended frequently for their chemotherapy.

This study is of great importance as research of this nature should be conducted regularly amongst the target group to develop the evidence based palliative care and to improve patient and family quality of care. It is hoped that the outcome of the research will provide basis for the establishment of Home Based Palliative Care for the advanced disease patients in the Centre.

Palliative Care often involves sensitive discussion of difficult issues and this was observed by the researcher through out the study while dealing with the patients in a way that will not stress the patients.

University of Cape Town

CHAPTER FOUR

FINDINGS AND RESULTS

A total of sixty – five questionnaires together with the patient information sheets were administered out of which three copies were incorrectly completed and rejected and eight were lost as the patients did not return to the next clinic appointment.

Sixty-five patients out of the 80 patients approached signed the informed consent forms before completing the questionnaire. The respondents were fully assured that their withdrawal from the study will in no way jeopardize their treatment. The period of the study was between June- August 2006 and successfully completed (54) questionnaires were used for data analysis.

4.1 ANALYSIS OF RESPONDENT'S CHARACTERISTICS

The researcher made use of descriptive statistical measures to produce the frequency tables and percentages in the analysis of the results.

4.1.1 BIODATA OF THE RESPONDENT

The data include the frequency, range, mean, median and standard deviation according to the respondents' age, including gender, tribe and religion.

There were more female respondents (66.6%) than males (33.4%), while 96.3% of the respondents were of Yoruba tribe and 59.3% were Muslims.

The respondents had an age range of 21-83, with a mean age of 45 and a median age of 40 respectively.

Table 1: DEMOGRAPHIC DATA

Table 1.1 Respondents Gender

	Frequency	%
SEX		
Male	18	33.4
Female	36	66.6

Figure 1.1 Respondents Gender

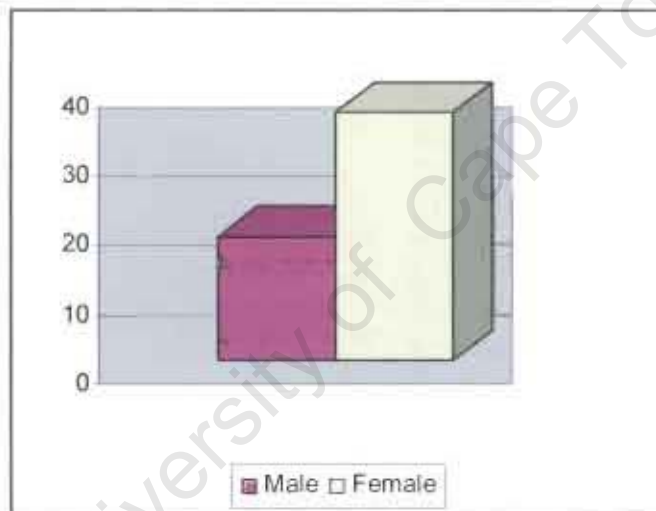


Table 1.2 Respondents Tribes

TRIBE	Frequency	%
Yoruba	52	96.3
Ibo	2	3.7

Table 1.3 Respondents Religion

RELIGION	Frequency	%
Christianity	22	40.7
Islam	32	59.3

Figure 1.2 Respondents Religion

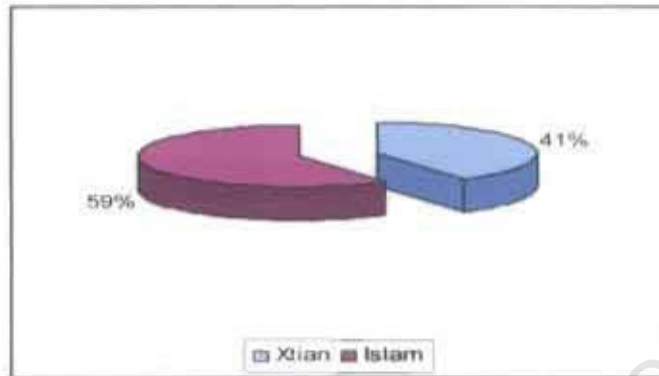


Table 1.4 Respondents Age

	N	Range	Minimum	Maximum	Mean	Std. Error	Std. Deviation	Median
Age	54	62.00	21.00	83.00	45.26	2.489	18.22313	40.0

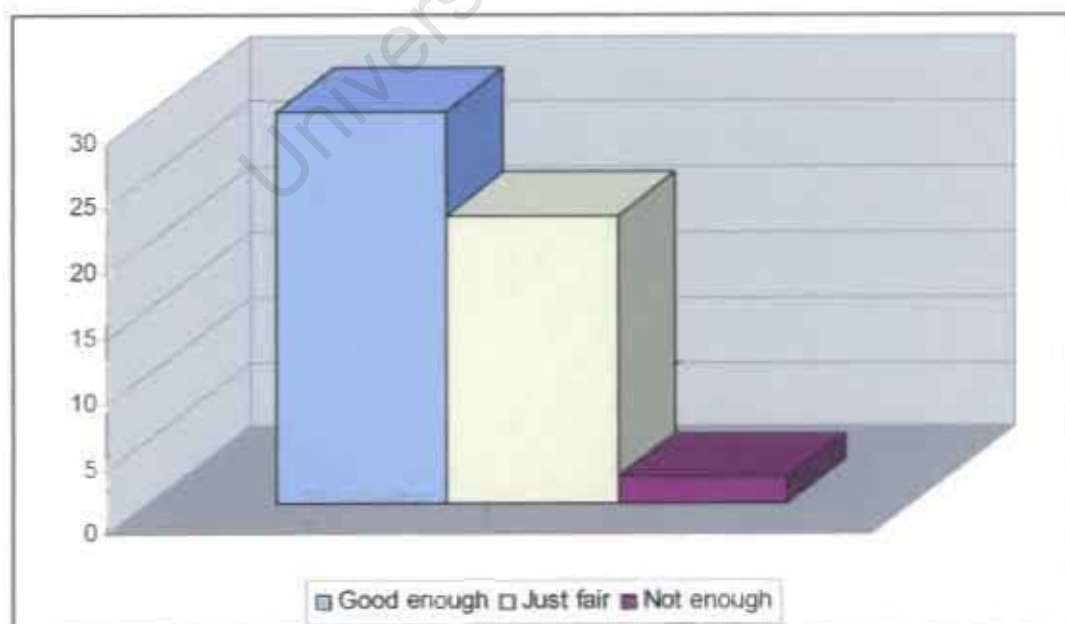
4.1.2 Respondents' opinion about the level of care for dying patients in Nigeria.

Thirty (55.6%) respondents were of the opinion that care of the dying patients in Nigeria is good enough.

Table 2: Assessment of Care of the dying in Nigeria

	Frequency	Percent
Good enough	30	55.6
Just fair	22	40.7
Not enough	2	3.7
Total	54	100.0

Figure 2: Care of the dying in Nigeria



4.1.3 Respondents' assessment of quality of care being received in the Hospital.

The Liker-type scale was used to measure an in depth importance and satisfaction of various needs of the respondents while in the hospital system.

- The respondents reported satisfaction of the physical, social, psychological, care offered by the hospital.
- Whereas, 29 (53.8%) of the respondents were not satisfied with the hospital aspect of spiritual care.
- Forty-six (85.2%) of patients were of the opinion that the hospital staff do not spend time with them while 27 (50%) of the respondents affirmed that they did not enjoy a close relationship with the staff.
- Thirty – two (59.3%) of the respondents claimed that the Health care providers do not share any information with them while 15 (27.8%) of the respondents are of the opinion that staff do not maintain privacy and confidentiality.

More than 50% of the respondents were not satisfied with both the spiritual and lack of closeness of the health care providers. Most respondents also observed that the staffs do not offer them the needed information about their disease conditions.

The Liker-type scale was used to measure the level of satisfaction of various needs of the respondents while in the hospital and the results are shown in Table 3

Table 3: Patient Assessment of the Hospital Quality of Care

	Strongly agree	agree	undecided	disagree	Strongly disagree
Physical Care	36 (66.7%)	18(33.3%)	-	-	-
Social Care	4 (7.4%)	39(72.2%)	2 (3.7%)	4 (7.4%)	-
Psychological Care	9 (16.7%)	39(72.2%)	2 (3.7%)	4 (7.4%)	-
Spiritual Care	4 (7.4%)	21(38.9%)	7 (13.0%)	19(35.2%)	3(5.6%)
Comforts	12 (22.2%)	36(66.7%)	3 (5.6%)	3 (5.6%)	-
Attention	4 (7.4%)	4 (7.4%)	17(31.5%)	26(48.1%)	3(5.6%)
Close relationship	14 (25.9%)	13(24.1%)	5(9.3%)	22(40.7%)	-
Information	5 (9.3%)	17(31.5%)	9(16.7%)	23(42.6%)	-
Privacy and confidentiality	12 (22.2%)	27(50.0%)	11(20.4%)	4 (7.4%)	-

4.1.4 Respondents' assessment of Hospital Staff and Costs.

The attitudes of hospital staff and their response time were commendable by the respondents but the hospital bureaucracy, patients' privacy and the hospital costs were not satisfactory.

Table 4: Assessment of the Hospital Costs and Staff attitudes.

	Good	Fair	Not desirable
Attitudes of staff	44(81.5%)	10(18.5%)	-
Response Time	45(83.3%)	6(11.1%)	3(5.6%)
Bureaucracy	15(27.8%)	37(68.5%)	2(3.7%)
Privacy	18(33.3%)	25(46.3%)	11(20.4%)
Hospital costs	7(13%)	25(46.3%)	22(40.7%)

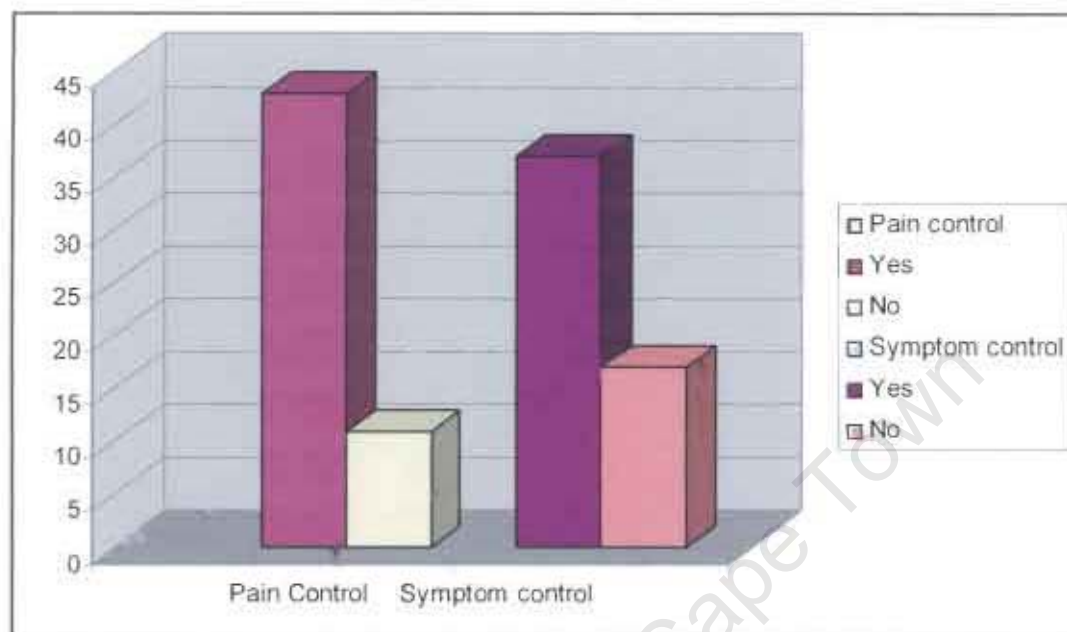
4.1.5 Perception of Home Based Palliative Care by the Respondents

The followings are the patients' expected needs at home and Respondents perception of the feasibility of providing them at home. HBPC counseling needs to the patients and community were also evaluated and there was an overwhelming support for its need by all the respondents.

Table 5: HBPC expectations at Home

	Yes	No	Total
Pain control at Home	43(79.6%)	11(20.4%)	54(100%)
Nursing care at Home	28(51.9%)	26(49.1%)	54(100%)
Symptoms control Home	37(68.5%)	17(31.5%)	54(100%)
Health Care team visits	46(88.9%)	6(11.1%)	54(100%)
Volunteers helping with house chores	39(72.2%)	15(27.8%)	54(100%)
Psychosocial and Spiritual counseling	45(83.3%)	9(16.7%)	54(100%)
Needed equipment and tools at home	-	54(100%)	54(100%)
Availability of basic drug needs at home	46(85.2%)	8(14.8%)	54(100%)
Planning future with Care givers e.g. burial	43(79.6%)	11(20.4%)	54(100%)
HBPC Counseling Needs			
Community and Patients	39 (72.2%)	15 (27.8%)	54(100%)
Life – threatening	40 (74.1%)	14 (25.9%)	54(100%)
Terminally – ill patients	8 (14.8%)	46 (85.2%)	54(100%)
On patient request	8 (14.8%)	46 (85.2%)	54(100%)
Not to be given at all	-	54 (100%)	54(100%)

Figure 3: Perception of HBPC and feasible Services at Home by the Respondents



4.1.6 Assessment of Respondents knowledge about Home care, relevance of HBPC in Nigeria diagnosis and attitudes of Health Care providers to their diagnosis.

Thirty - two (59.3%) of the respondents are aware that advanced disease patients can be taken care of at home while 77.8% are not aware of any formal Home Based Palliative Care in Nigeria.

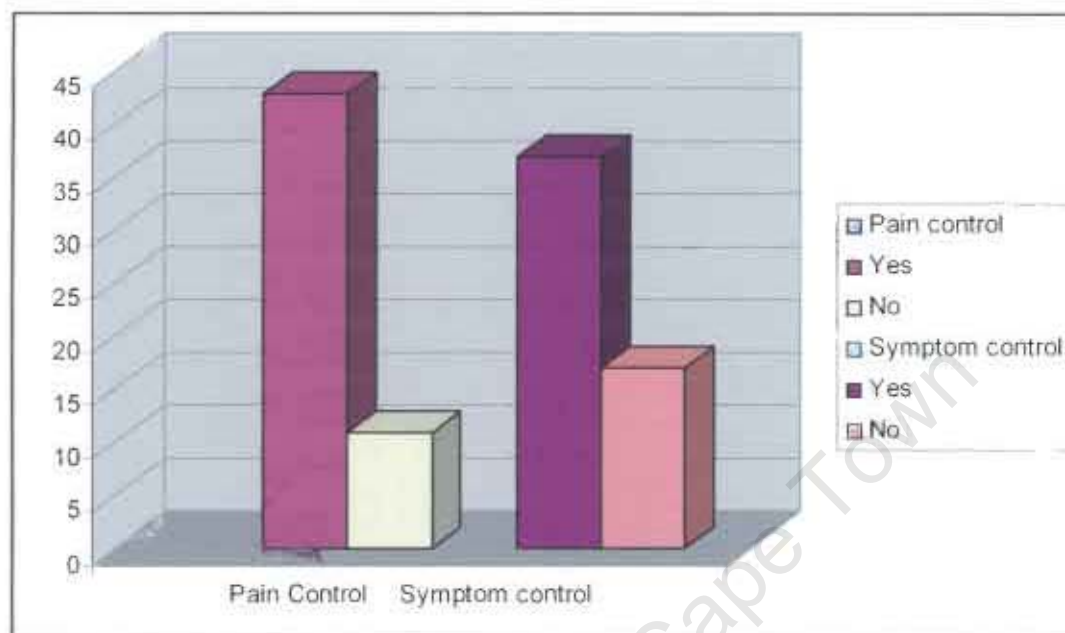
A significant number of the respondents do not believe they can receive better care at home and hence do not want wish to have HBPC. However, it is worthy of note that all the respondents believe the establishment of HBPC in Nigeria is relevant.

Thirty (55.6%) of them have knowledge about their diagnosis and 74.1% of the respondents experience some discrimination from the hospital staff although they offer them good attention.

Table 6: Respondents awareness Home Care and their diagnosis

Aware of Home Treatment	Frequency	%
Yes	32	59.3
No	22	40.7
Aware of Home Based PC.		
Yes	12	22.2
No	42	77.8
Believe can receive better care t home		
Yes	17	31.5
No	34	68.5
Respondents wish to receive home care		
Yes	21	38.9
No	33	61.1
HBPC relevance in Nigeria - Yes	54	(100%)
Aware of Diagnosis		
Yes	30	55.6
No	24	44.4
Health Care Team providing attention		
Yes	54	100
No	-	-
Discrimination by Staff		
Yes	40	74.1
No	14	25.9

Figure 4: Respondents awareness and knowledge of HBPC



4.1.7 Needs Assessment of Health Care Team Required by Respondents at Home

Majority of the respondents believed in the need for multidisciplinary professionals to visit them at home if need be, as shown in this table.

Table 7: Respondents Health Care Team needs assessment

	Yes	No
Doctors	45(83.3%)	9(16.7%)
Nurses	45(83.3%)	9(16.7%)
Social workers	51(94.4%)	3(5.6%)
Physiotherapists	42(77.8%)	12(22.2%)
Spiritualist	46(85.2%)	8(14.8%)
Volunteers	49(90.7%)	5(9.3%)

4.2 REVIEW OF THE OPEN –ENDED COMMENTS OF THE RESPONDENTS

There were many responses to the open - ended questions by the respondents as to their advice and need to setting - up Home Based Care for advanced disease patients attending the Centre;

A **qualitative thematic analysis** of these open - ended comments of the respondents derived four (4) themes that further re-enforced and corroborated the perception and needs of Home Based Palliative Care among the target group. The four themes were:

- 1) The cost implication of the Home Based Palliative Care
- 2) Respondents reservation about the model of care
- 3) The perceived or expected benefits.
- 4) The respondents' perceived relevance of HBPC to Nigeria health system

These aspects are shown below:

Table 8. Table of themes and sub-themes developed in data analysis.

Theme One	Theme Two	Theme Three	Theme Four
Cost implications of HBPC	Reservation for HBPC	Perceived benefits of HBPC	Perceived relevance of HBPC
1.1 Affordability	1.1 Acceptability	1.1 Home stay	1.1 Importance and needs
1.2 Chance to have alternative therapy	1.2 Confidentiality	1.2 Health to Community	1.2 Government role

Theme ONE

Cost implication of Home Based Care (HBPC) to recipients as expressed by the respondents interviewed.

1.1 Affordability of HBPC

Some of the respondents wonder whether the cost of HBPC will be “affordable”, the orthodox care in Nigeria is “pay for service”. This arrangement has made health care service out of reach and sometimes inaccessible to the indigent.

One of the respondents that have been finding it difficult to cope with the hospital bill asked:

“Do you think I will be able to afford the cost of treatment and who is going to pay the doctors whenever they come home to treat”.

Another respondent commented:

“ I am too weak to work and unemployed with no source of livelihood”,

“Is there anyway the government may assist to pay as I am already a big burden to my family”

1.2 Home Care is expected to offer some flexibility, an opportunity to access Alternative Therapy.

A respondent stated that *“I believe this would be an opportunity to combine alternative medicine and lower cost of care”.*

“The hospital staffs always frown and discourage me to use local herbs and I believe it works and cheaper, this I can try at home”.

Theme TWO

Reservations about HBPC services:

2.1 Fear of acceptability

Some respondents were fearful on the success of this new model of care. Their argument and fear is the usual difficulty in starting a new concept or project and the un-predictability of the recipients. Some strongly advise a gradual implementation and encourage us to exercise some caution while visiting patients at home – A respondent expressed her feelings as follows:

“People can be very unpredictable and as you know, our people may be funny I advise you exercise caution while giving the service”.

“It will affect my privacy and I am not a good host”

“I will prefer coming to the hospital as usual, it makes me feel better”

In a situation where the Health care provider wants to offer a positive help or assistance at home whereas the recipient may have evil intentions that may injured or harm the care giver and a respondents sounds a word of caution. Some of the respondents actually find it difficult to imagine the health workers coming home maybe because it has never existed in our culture.

Confidentiality and Privacy issues

. Others were afraid of the Health Care providers infringing on their privacy and confidentiality and that their neighbours would become aware of their diagnosis.

A respondent fears that - *“Do you mean your people can come to my house anytime, that will be nice but I am really a shy person”*. Another respondent clarifies this bluntly and claimed - *“Confidentiality will be nil, I do not support this because my neighbours will be suspicious of your coming”*.

“Everybody around will start asking questions and want to know the details of my illness”

“Honestly, I prefer that people should not know even my husband as we are three wives”.

Theme THREE

Perceived Benefits of HBPC by the Respondents

3.1 Home stay:

The following benefits and advantages were identified by some respondents; some believe it will be an opportunity to stay at home with their families and emphasize its convenience. This they expect to motivate the patients and serve to encourage their active participation in their health care plan. This is reflected in one of the respondents contributions:

‘It will be an opportunity to stay at home and a sort of change from the hospital environment’.

4.2 Government Role

Some of the respondents pray to God and the Government to implement the services and provide funds to establish it as it is being done in other countries – – ***“I believe our government should provide Home Care just like other countries”,***

These findings and various respondents’ submissions put no one in doubt of the need and relevance of HBPC in the country to improve the quality of care and life of people suffering from life threatening disease in the country.

It has also confirmed their interests in accessing Home Based Care if available. This can be extrapolated from this respondent’s view that ***“It is my sincere prayer that God will enable you people to provide Home Care as it will be more convenient to the patients”***

“Nigeria government is not doing enough about our health in this country, they should play a significant role in this home care”

CHAPTER 5

DISCUSSION

This research study is designed to create a baseline data on the awareness and needs assessment of HBPC among the target group. It was revealed that most of the advanced disease patients receiving treatment at the Centre were not aware of HBPC and they felt strongly convinced that there is a need for such program in our society.

HBPC is at an early stage of development in the country despite the fact that the first Hospice (Nigeria Hospice) was established in the early 1990s, there had been no significant achievement on this model of care in the country. However, the Hospital based Palliative Care services of some teaching hospitals like Zaria Palliative Care Centre and University College hospital Ibadan have both made a bold step in the provision of this model of care. The Federal Medical Centre Abeokuta Hospice and Palliative Care Services has been offering hospital based Palliative Care since 2001 and is now in the planning stage to extend its services to the community by introducing Home Based Palliative Care and hence the Needs assessment before embarking on the HBPC project.

5.1 Patient assessment of the Hospital quality of care and Costs

Is there really a need for an alternative model of care outside the hospital for patients suffering from life – threatening diseases and are there any unmet needs?

Initial assessment of the existing level of satisfaction of hospital care or services being offered for this target group is crucial to identify any inadequacy before any alternative suggestion like HBPC is offered. A significant number of respondents are satisfied with the comfort, physical and psychological care experienced or offered to them by the hospital. This is an attestation to the efficiency of the level of care or services being rendered by the hospital. The finding was further corroborated on the assessment of the attitudes of the staff and their response time which were rated as efficient.

Most respondents were not satisfied with the hospital bureaucracy, their complaints include hierarchical bottom – up approach attendance by the junior doctors up to the hospital Consultants and burdensome investigations. Other problems identified in some studies include long queues at the paying points, prolonged admission, lack of sympathy, rigid hospital time table and hospital meals [16]. It was significant to note that the respondents are dissatisfied with the lack of good rapport, and that the staffs are not sensitive to patients' privacy and other confidentiality issues. The respondents also commented on the lack of spiritual care by the hospital. Spiritual care is recognized as important in assisting the patients in finding meaning to their illness.

The patients also commented that information on their disease diagnosis, prognosis and care plan was not provided to them. This paternalistic attitude contradicts the principle of patient autonomy which ideally empowers the patient to contribute meaning fully to the care plan as expected in palliative care practice.

Thirty –two (59.3%) of the respondents were satisfied with the hospital bills especially the HIV/AIDS patients receiving free treatment however cancer patients identified that the bills are expensive. Hospital based services are generally more expensive than HBPC although most patients in the study appear to be comfortable with the hospital costs. The Hospital is designated as one of the few privileged centres in the country that offers free HAART drugs and laboratory services to the HIV/AIDS patients. The cancer patients do not enjoy such subsidies and are solely responsible for their own bills, drugs and laboratory costs and may as well regard the hospital bill relatively expensive unlike the HIV/AIDS patients. Beck in his study actually confirmed a lower cost of HBPC compare to hospital costs. The expected low cost of HBPC services maybe an advantage to such patients in Nigeria and other African countries in low resource economy.

This study has confirmed the respondents satisfaction with the disease specific (physical) and psychosocial care being offered in the hospital but were not comfortable with the supportive care. Some of these identified defaults like hospital bureaucracy, non - sharing of information, lack of privacy and other confidentiality issues could possibly be rectified by training the staff the needed palliative care principles, setting up a hospital based palliative care team and good Home Based Palliative Care program.

HBPC also offers the Health care providers an ample time to relate, get closer and fully support the patients and their families while at home. It is more advantageous for patients with chronic or terminal illness compared to the hospital care where the staff concentrate more on acute cases and neglect chronic cases which are often regarded as hopeless.

Jody Oesterreicher's study in USA found out that health care team home visitation offers a better clinical judgment and more rewarding to both parties feeling at home unlike in the busy hospital practice [45].

5.2 PERCEPTION OF HOME BASED PALLIATIVE CARE

The respondents believed the existing level of care for the dying in the whole country is adequate. This perception may be influenced as the respondents are not aware of alternative models of care.

The care for dying patients as experienced by the respondents lacks adequate pain control as opioids are not easily available or accessible and neither does it include holistic care approach. Some respondents believed that seriously ill patients could be treated at home locally by the family. The traditional home care for dying patients usually for the geriatrics patients involves keeping them at home while the family and neighbours take care of them without any professional involvement and the family care at home is not able to provide pain control.

It is not surprising that more patients are dying in our hospitals as in the Western countries where deaths had been "medicalised and institutionalised" with more people dying in the hospital than at home.

However, previous studies showed that more deaths are likely to occur at home in rural areas compare to urban communities which may be directly due to limited access to health facility in the rural areas. [81].

This change of attitude is also noticeable here in Nigeria as some families do transfer their patient back to hospital for re-admission as soon as they can no more cope at home especially in advance disease conditions. It has been observed that wealthy families and politicians prefer to fly their sick family members abroad even when there is little hope of survival. The provision of good palliative care at home may reduce some of these re-admissions and unnecessary transfer of patients abroad for treatment [82].

None of the respondents believed it is feasible to provide the needed equipment for HBPC at home. This is expected in a country where there is scarcity of needed hospital equipment in the formal health facilities and as such difficult to imagine the availability of this equipment in a model of care that has never existed in the country. Although, it needs to be appreciated that HBPC is not a technologically hi-tech requirement but the fact remains that the provision and availability of equipment may be a challenge in setting up HBPC in the country.

The respondents' opinion that advanced disease patients can be taken care of at home is a good indication of potential support and a good platform on which a formal HBPC can be built in the country. Our traditional communal culture of the extended family of taking care of the sick and the spirit of good neighbourliness may be an advantage.

Health care providers will have the opportunity to offer their skills and knowledge to complement the effort of the families and neighbours in taking care of such patients at home.

It was also recognised that the majority of the respondents believed that the provision of basic palliative care services like pain control, symptom control, nursing care, psychosocial care, spiritual care, volunteers helping hand, health care team visits, basic drug requirement and joint planning of future care with patients and care givers is feasible at home. It is therefore necessary to sensitize, advocate, educate and put in place an efficient Home Based Palliative Care program in Nigeria so that the people can benefit and access these services.

Majority of the respondents have never heard of any Home Based Care program in the country and only a few of them had such information during the course of their interaction with the researcher especially those referred to the Hospital Palliative Care Team while others also heard of HBPC from the media like TV, Radio, and Newspaper.

This finding was in contrast to the awareness research done by Turner among the American Indians and White elderly in the US, where most of the respondents knew about HBC through referrals and friends maybe because the practice was already entrenched in their own health system [83] unlike what happens here in Nigeria.

The study confirmed that most of the respondents are not aware or have never witnessed a formal HBPC program including those who claimed to have heard about the program. This is not surprising as Palliative Care is still at a developmental stage in the country; this finding supports the study done by Adenipekun and his group at the University College Hospital in Ibadan, Nigeria which confirmed a gross lack of knowledge about Palliative Care and Hospice in Nigeria community [23].

Another study done in Nigeria by Adebayo also confirmed and recognized the need for community home – based care activities but find out that there was dearth of information about Home based care in the country[80].

5.3 NEEDS ASSESSMENT OF HOME BASED PALLIATIVE CARE

In this study, some of the respondents were aware of their diagnosis and these were the HIV patients attending the ARV Clinic whereas most of the cancer patients are not aware of their diagnosis. This is the usual experience, as majority of patients suffering from life – threatening conditions are never told of their diagnosis in an attempt to protect them. Although it was noted that some of the inpatients both cancer and HIV/AIDS patients at times deny a prior knowledge of their diagnosis. These findings do not impact too negatively on the study as most of the respondents were aware of their diagnosis but prefer to have more detailed information which are not easily available in acute care services compare to what obtains in palliative care centres.

Denial of the disease knowledge, feigning ignorance and difficulty in rationalizing or accepting the unexpected diagnosis may be explained with Kubler theories [84].

Sometimes both the family and the doctors may enter into conspiracy of silence and refuse to inform the patient. This often leads to a distress and feelings of hopelessness as the patient unilaterally try to cope with the illness. The failure to break the bad news may also be due to lack of adequate communication skills on the part of the doctor. [85].

Although not much work has been done in this area in Nigeria but it is estimated that 60% of family members will not want a full disclosure to their patients while up to 50-90% will prefer full disclosure in developed world.[86, 87].

It is the right of every patient to know his diagnosis, prognosis, treatment and care plans. The expected rapport and investment of enough time by the health care providers on visiting the patient at home is supposed to encourage family meeting, sharing information and educating the patient and the family about the disease condition. This is in a sharp contrast to what obtains in the hospital known for the usual short period of interaction especially at the clinics. Johnson, in his study also emphasized this by sounding a word of warning that the “shift of our focus from institutional to community settings of care, must never lose sight of the fact that when we enter the homes of our clients, regardless of our role, we are guests. And it is in that role, that we must, when necessary, put aside our loyalty to traditional approaches to care and open our hearts and minds to the direction and needs of those who chose to die at home [88].

Discrimination and stigmatization have always been associated with disease conditions like cancer and HIV/AIDS. The respondents confirmed this although this attitude had been drastically reduced in the Centre. Social and self stigmatization among the HIV/AIDS patients is gradually becoming less of a problem with good Voluntary Counseling and Testing (VCT) coupled with the interdisciplinary team care approach introduced by the Palliative care team.

In a study by Chilamba on the provision of Community and Home Based Care in the rural Zambia, the program was able to eliminate stigmatization attached to HIV/AIDS, confidentiality sharing and responsibility sharing with improved community participation were the benefits [89]. Ncama in her study also found that there was a positive attitudinal change towards HIV/AIDS and a better knowledge of the disease among those patients that had accessed Integrated Community Hospice and Palliative Care services in South Africa [44].

A significant number of the respondents believed they can get a better care at home especially the cancer patients but the HIV/AIDS patients are reluctant to consider the possibility of home based care as the issue of disclosure is still a problem in our society. The open-ended response of some of the HIV/AIDS patients further confirmed their reluctance to accept home visiting. One of the respondents suffering from cancer felt that HBPC will offer him an opportunity to combine alternative therapy like visiting herbalist and spiritualist.

The alternative therapy has never being supported in the hospital but as soon as the patients realize the futility of hospital care they tend to seek alternative approach believing that the disease condition maybe spiritual or as a result of witchcraft.

The study has confirmed that some respondents are interested accessing Home Based Palliative Care services. However there a few of the respondents who expressed some negative feelings that their neighbours may be wondering what is really going on if they are to be visited at home with the fear that it may affect both their confidentiality and privacy.

Improved social awareness and advocacy may facilitate acceptance of HBPC which was supported by the respondents as they all prefer and recommend that it should be extended not only to people suffering from life threatening conditions but also to the entire community.

All the respondents prefer a comprehensive implementation of palliative care components into the HBPC service like pain and symptom control, home visits by health workers and volunteers, availability of basic drugs, nursing, psychosocial and spiritual care.

The study also showed that all the respondents would choose to be visited at home by multidisciplinary team consisting of Doctors, Nurses, Social workers, Physiotherapists Religious leaders and Volunteers.

The expected HBPC benefits like improved patient quality of life at home, expected reduced costs, reduction of pressures on the hospital facilities, stigma reduction and empowerment of the patients and family in care plan will be to a great advantage HIV/AIDS and cancer patients.

It is to be expected that none of the respondents knew of any standing Home Based Palliative Care program in the country since Palliative Care is still at a developmental stage. The needs and relevance of HBPC in the country have been explored by this study and it has no doubt been confirmed by the respondents.

Respondents health care behaviours

Although the scope of this study is outside a formal costing of care but the patients' perception of affordability of care is an important issue as it sometimes affect their health care behaviours.

The subject poverty in the country often contributes to the late presentation or rather patient reluctance to present at the hospital on time. They often prefer to explore other perceived solutions like traditional healers, spiritualist expecting a lower cost. The patients often run the risk of exhausting their meager resources seeking alternative solutions and later consider the hospital as the last ray of hope. In Nigeria, the alternative medicine practitioners advertised openly in buses, marketplaces, in the newspapers, radio and televisions and are daily gaining popularity claiming all sorts of cure. Their costs are lower and do not involve burdensome laboratory investigations and cost of admissions making their services attractive.

Some patients often wish to combine both orthodox and alternative medicine but this is never allowed in the hospital. Patients desperately consider this alternative options to save costs when the health care providers said “there is nothing more they can do” and especially at that frustrating point when they do not have enough money to continue with orthodox treatment. The expected low costs of the HBPC with the unlimited and uninhibited access to alternative therapy at home maybe an advantage and cost saving to patients.

Confidentiality and Privacy issues

This is a very big concern to most patients because of the risk of social stigmatization and discrimination which is not only peculiar to Nigeria. A similar incidence occurred to Home Care team in Uganda whereby a patient asked the team to always park their vehicles about three streets away from home her as some neighbours have been asking her questions about the mission of the visiting team who always park in front of her house.

It is similar in other African culture as the neighbours always show concerns and care like wanting to know what is happening to others with a view to offering assistance. However, some Palliative care patients do not want people to know of their true disease condition for the fear of stigmatization.

A significant number of respondents especially the cancer patients indicated their interests in accessing Home Based Palliative Care services while others expressed some

concerns that their neighbours may be wondering what is really going on if they are to be visited at home as it may affect their confidentiality and privacy.

This study confirms the lack of awareness of a formal HBPC and the obvious non – existing practice of HBPC care in the country. The respondents supported the need and relevance of HBPC in the country to improve the quality of care and life of people suffering from life threatening disease in the country.

The general consensus of all the fifty- four respondents is that the establishment of Home Based Palliative Care is timeous and very relevant to the needs of people suffering from life - threatening diseases in the country.

5.4 LIMITATION OF THE STUDY

These include few numbers of available patients that falls within the target group (few numbers of life-threatening conditions compare to other acute cases) and the short period of time of the study. Other limitations include the challenges of combining the study with a full time routine clinical works. The use of hospital palliative care team in administering the questionnaires pose the risk of biased which can not be entirely ruled out. This was minimized to some extent by the previous training in Research ethics in palliative care attitude including sensitivity to patients concerns and the administration of the data collection tool prior to the commencement of the study. Some patients were requesting for what would be their gain or incentives by participating in this study and this actually influenced their zeal.

CHAPTER 6

CONCLUSION AND RECOMMENDATION

6.1 CONCLUSION

This study confirms the objectives of this study by evaluating the level of awareness, perception and needs assessment of home based palliative care among the respondents.

a) It has confirmed a low level of awareness of HBPC among patients with life threatening illness attending Federal Medical Centre, Abeokuta, Nigeria.

b) The study revealed that most of the respondents first learnt about Home Based Care during the course of this research and the study had been able to sensitize the patients about the benefits of HBPC.

c) It has also shown that there is an urgent need to establish and implement Home Based Palliative Care in the country judging by the open ended comments of the respondents.

The research also re-emphasised and confirmed the perceived inadequacies of the hospital as their staff do not have enough time to spend or socialize with the patients. Their observation was that staffs were too distant and tended to discriminate and withhold vital information about their health concerning their diagnosis, prognosis and there was a lack of other necessary supportive care like spiritual issues.

It is believed that HBPC services for terminally ill patients will to some extent reverse or improve upon some of the frustration as expressed by the patients. There is need for an alternative approach or model of care that can improve on the highlighted defaults in the hospital setting. If HBPC is taken home to the patients it would provide an ample opportunity for the Health Care providers to fully support, interact better and involve the patients and the family in the Care plan. The study had also explored and evaluated the patients' expectations and their needs concerning HBPC besides highlighting their fears and anxieties..

6.2 SUMMARY

The study has supported a strong recommendation to create the **awareness** of HBPC in the country and to introduce this model of care. One of the benefits of this study was that it had successfully sensitize a reasonable level awareness of the existence of such program among the respondents besides identifying and address the inadequacies in the hospital which can be easily corrected with the Home Care concept. All the respondents were favorably dispose to embracing this model of care as they all agree to its relevance in the care for life threatening disease patients in Nigeria. This research has reinforced and re-emphasize the **need** for the establishment of Home Based Care program for the advanced disease patients attending Federal Medical Centre Abeokuta, Nigeria and others scattered all over the country.

6.3 RECOMMENDATIONS

The following recommendations based on the comprehensive appraisal of the study may help to establish Home Based Palliative Care and bring Palliative Care nearer home to the patients and their family:

- There is an urgent need for the government and the health care providers to organize a situational analysis of Palliative care needs or burden across the country at large.
- Public education and advocacy on the relevance of HBPC to the policy makers, community leaders, their people, various religious groups and health care providers in the country.
- Integration of Palliative Care into the National Health Policy as prescribed by the World Health Organisation (WHO) is long over due.
- The National Palliative Care guidelines for cancer and HIV/AIDS should include HBPC as a vital component of the service.
- Government should put in place the necessary funding and infrastructure needed to establish HBPC all over the country.
- Manpower training of all the Health care providers and inclusion of Palliative Care into the medical and nursing curriculum.
- The existing Primary and local government health care facility and the cultural extended family may be an asset to effective implementation of these services.

6.4 SUGGESTIONS FOR FURTHER STUDIES

A much large scale study should be done using a Multi - centre approach. It is also pertinent to survey the perception and needs assessment of Home Based Care among the Health Care providers and the Care givers in the nearest future. This is to equally sensitize them and confirm whether they would be ready to embrace the model of Care as they are the major stake holders in its future implementation.

There is need to implement further studies to determine patients' knowledge of alternative models of care and once the HBPC services have been established to compare the level of satisfaction with hospital and HBPC.

CHAPTER SEVEN

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11. The hospital addresses the following needs for patients with advanced disease. Please tick the response that most closely meets your experience for each aspect of care.

	Strongly Agree	Agree	Do not Agree or Do not Disagree	Disagree	Strongly Disagree
Physical					
Social					
Psychological					
Spiritual					
Comforts					
Company					
Intimate relationship					
Information					
Privacy and confidentiality					

12. Do you get enough attention from the health workers while on admission?
YES / NO

13. Do you experience discrimination at the hospital?
YES / NO

14. Hospital performance assists patients in accessing care. Please tick the box that most nearly reflects your experience.

	GOOD	FAIR	POOR
Attitudes of staff			
Bureaucracy			
Privacy			
Costs			Expensive
Response time			

**18. Do you think it is relevant to offer Home based care in Nigeria?
YES / NO / DON'T KNOW**

19. For patients with advanced disease condition, when should information about Home - based Care option be given?

	YES	NO
It should not be given at any point		
Information should be available to community members and not given to the patient		
It should be given to the patient when serious illness is diagnosed.		
It should be provided only if advanced disease became terminal		
It should be provided only at the patients request		

**20. Are you aware of any home based care organization that provides patient care?
YES / NO**

21. Do you have any other comments or concerns about accessing home based care services?

.....
.....

APPENDIX 2 TRANSLATED QUESTIONNAIRE

**IWADI IMO NIPA IPESE - IWOSAN ABE - ILE, FUN AWON TI O NI AISAN
TI O LE GBA EMLTI WON NGBA ITOJU NI FEDERAL MEDICAL CENTRE,
ABEOKUTA, NIGERIA.**

Ipese Iwosan abe - Ile je okan la ra ipese iwosan gbogbo ise eyi ti o gboro ju lo fun awon alaisan baraku ati awon idile won. Iwadi imo yi ni lati se awari oye awon alaisan nipa ipese iwosan fun won ninu- ile ati awon n kan ti o ye lati pese fun asejori l ati mu iwosan to won lo ni ile. Ti e ba faramo mo lati ko ipa ninu iwadi yi, e ma fi owo si iwe. Lehin eyi ni a ma bere awon ibere nipa yin. Ti e ko ba ni ife ati ko ipa ninu iwadi na, ki yio pa itoju yin lara.

A dupe lowon yin.

Jo wo fi idahun si awon ibere won yi;

- 1) Omo odun me lo ni yin : odun
- 2) Okunrin ni yin tabi Obinrin:
- 3) Iru e lesin wo ni yin : Igbagbo / Musulumi / Esin ibile
- 4) E ya wo ni yin: Yoruba / Hausa / Igbo
- 5) N je mo iru aisan ti o nse yin ati nkan ti o fa aisan na ? Be eni / Be eko
- 6) N je e ni igbagbo pe itoju awon alaisan baraku ni orilede yi dara to?
O da to / o da die / ko da to
- 7) Se e ni igbagbo wipe awon alaisan baraku le gba iwosan ninu ile won?
Be eni/ Be eko
- 8) N je eyin le fa ra mo lati gba itoju ninu ile? Be ni / Be ko
- 9) Se e ti gbo ni pa itoju ninu ile fun awon alaisan baraku ri?
Be ni / Be ko
- 10) Ti e ba ti gbo ni pa itoju yi ri, e so ibi ti e ti gbo?

Eyin ti kara yin / Ebi / Ore ti o ti gba iwosan yi ri / E ti sise ni ibi ipese iwosan yi / Lori ero a ya ra bi Asa (Internet) / Iwe iwadi ijinle / I pade- idanileko / Ile – eko dokita / tabi ile – eko olutoju alaisan (Nurse) / Lori ero asoro-magbesi / amohun-maworan/ iwe iroyin.

Da oruko O na miran

11) Ile iwosan ma nse ipese awon eto won yi fun awon alaisan baraku ?
Ki e mu idahun ti o fi ara jo iriri yin ninu awon yi.

	Mo fi gbogbo ara gba	Mo gba	Mio gba Tabi Mi o ja won ni iyan	Mi o gba	Mi o fi gbogbo ara gba	Mi o mo
Ailera						
Iba ni da ra po / ibani sere						
Itoju Ai - lera okan						
La ti sun moOlorun						
Ipese- Itura / iroran						
Iduro ti ni						
Ife, irepo ati ifa - nimora						
Ijiroro						
Isimi lai si iyonu ati bibo asiri						

12) Se awon Olutoju alaisan n fun yin ni amojuto to pe ye nigba ti e wa ni
Ile iwosan? Be eni / Be eko

13) Nje o se alabapade Iwa iya-si oto tabi ipati ni Ile-iwosan?

Be eni / Be eko

APPENDIX 3

Informed Consent.

Participant Information

Researchers at Federal Medical Centre, Abeokuta are conducting a study to determine the perception and needs assessment of Home based care among Patients suffering from advance disease conditions attending this hospital. If you agree to participate, you will be asked to provide some information about yourself and the type of care you would prefer to have at home.

As a participant in the research, you will receive all the usual care as required in this hospital without any form of discrimination. The results from this research will enable us to provide information about the requirements needed to provide care at home for people suffering from life threatening conditions.

Any information you provide will be kept confidential and will not be used against you.

If you decide not to participate, the treatment for your illness will not be different as you will receive all the usual care. You are free to choose whether or not you wish to participate. You are also free to discontinue your participation in the course of the interview at any time.

**We hope you will participate and thank you if you do
Do you have any question about the research?**

**Please feel free to contact; Dr. B.O KEHINDE
Federal Medical Centre
Abeokuta.
Tel- 08056551035.**

**Research Scientist;
DR. FOLAJU O. OYEBOLA
Federal Medical Centre
Abeokuta.
Tel – 0803711869**

IWE-IFOWOSI

Emini da ni loju wipe:

A ti se alaye Iwadi yi fun mi, ohun ti won nse iwadi le si ye mi dada.

Mo si mo wipe mo le yonda ara mi kuro ninu iwadi yi nigbakugba ti ko si ni pa itoju mi lara.

Mo si mo wipe awon idahun mi ma ni asiri ti enikankan ko le mo nipa.

Mo gba lati ko ipa ninu iwadi iwulo ipese itoju ninu ile fun awon alaisan ti o ngba itoju ni ile iwosan ijoba apapo ti Federal Medical Centre Abeokuta.

.....
Ifowosi iwe / ika tite olukopa

.....
Ojo

.....
Ifowo si iwe oni Iwadi

.....
Ojo



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MBChB, MRCS, FRCR, FRCGP

Asst. Director of Admin

Mr. C.S. Oyele
BSc, MPA, AMNIM, AIPM, J

Our Ref: FMCA/236

Your Ref: _____

Date: 23rd Fe

Dr. F. O. Oyabola - Consultant Spec. Grd I
Anaesthesia Dept.
Federal Medical Centre
Abokuta

ETHICAL APPROVAL ON A PROJECT ON "A PERCEPTION AND NEEDS ASSESSMENT SURVEY OF HOME BASED CARE AMONG PATIENTS WITH ADVANCED STAGE DISEASE ATTENDING THE FEDERAL MEDICAL CENTRE ABOKUTA"

Please refer to your request for approval to study the above-named project.

The FMCA Ethical Committee at its meeting of 23rd February, 2006 has approved the proposed project having observed that the study does not contravene any laws and regulations guiding experiments in human subjects.

The Committee has therefore approved your request to commence the study.

However, you should feel free to inform the Committee of any change during the course of the study and that a copy of the project should be forwarded to the Chairman of the Committee upon completion of your study.

Thank you.

[Signature]
23/2/06

Dr. J.K.L. Osinfade
Head of Clinical Services