

THE PRACTICE OF PALLIATIVE CARE MEDICINE IN THE DEVELOPING WORLD: A REVIEW OF THE CHALLENGES IN PROVIDING PALLIATIVE CARE SERVICES IN SOUTH-SOUTH NIGERIA

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ABSTRACT

Background: Palliative Care Medicine is an emerging specialist discipline with most of the services located in developed countries and very few or none in low and medium-income countries. Developing countries, however, have higher incidences of cancer and HIV/AIDS and most of these patients would benefit from palliative care. Regardless of the burden of life-limiting illnesses, only very few countries in Africa have well established, culturally accepted palliative care services.

Aim: This article aims to review the practice of Palliative Care Medicine in developing countries vis-a - viz the challenges in providing palliative care services in South-South Nigeria.

Materials and Methods: The literature search was done using the key words, 'Palliative care', 'end-of-life care', 'life-limiting illnesses', 'developing countries', and challenges as contained in this article, without limitation to year of publication.

Results: In this review, the challenges of palliative care practice in developing countries like Nigeria are due mostly to lack of Government policy, funding, manpower, availability, and acceptability of opioids especially morphine for proper pain management. These are the same challenges that affects the provision of palliative in the South-South region of the country.

Conclusion: Palliative care medicine in the South-South region of Nigerian is almost non-existing, the government of Nigeria and the international community need to assist in the development of culturally acceptable palliative care services to this part of the country to help improve the quality of life of those suffering from life-limiting illnesses and their families.

Keywords: Palliative care; end-of-life care, life- limiting illnesses, developing countries, challenges



INTRODUCTION

Despite the fact that Palliative care medicine is almost non- existing in most of the developing countries, the burden of life-limiting illnesses is now a public health issue worldwide especially in low and medium income countries (LMICs).¹ Life-limiting illnesses are disease conditions that currently have no cure which the individual will live with till they die. These disease conditions are also known as life-threatening illnesses and the complications associated with them will inevitably lead to death of the individual. These include most cancers, HIV/AIDS and other non-communicable diseases.² All patients with life-limiting illnesses would need palliative care.

Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-limiting illnesses. It prevents and relieves any physical, psychological, social, or spiritual suffering experienced by adults and children living with life-limiting health problems through the early identification, correct assessment, and treatment of pain and other problems.³ It provides holistic care to these patients by not only treating the body but the soul and spirit. It also reaches out to the family members. It involves the use of multidisciplinary terms to provide comprehensive care for the patient and family which can be provided in a hospital, hospice or at home.³ The essential practices in primary palliative care comprise of physical care, psychological/emotional /spiritual care, care planning/ coordination, and communication.⁴

It is about living as well as dying with dignity. Therefore, it is a good practice for all who require this type of care to be referred early by their physician. Although Palliative care is often referred to as end-of-life care, when properly carried out, it has been found to improve outcomes of patients with terminal diseases even leading to increased survival. The focus is not on death, but on compassionate specialized care for the living which results in improved quality of life.^{4,5}

Palliative care should be applied at the point of diagnosis and continued when all curative therapies have failed in patients with life-limiting illnesses. It does not seek to prolong life but to improve the quality of life of the patient until death. However, there is evidence that has shown that most patients with life-limiting illnesses that have access to palliative care early, enjoy an improved quality of life and as a result, live longer than was expected.^{4,5}

An estimated 40 million people require palliative care worldwide, approximately 78% of them live in low and middle-income countries and only 14% of people who need palliative care currently receive it.¹ Notwithstanding this great need, the current provision of palliative care in Africa is inconsistent and access to culturally appropriate, holistic palliative care is at least limited and at most non- existent.^{1,5} Even though, WHO had presented that palliative care should be integrated into all nations' health care system in 2002, several African countries including Nigeria are yet to approve it as a policy.⁵ As a result of this, palliative care development in Nigeria is very

slow and does not exist in most parts of the country. Many centers that offer palliative care are mostly tertiary institutions that are located more often in urban areas with none in the rural areas. Also, many centers lack radiotherapy machines and where they have the machines are often not functional. There is no functional radiotherapy machine in the south-south of Nigeria. Even access to morphine is difficult in rural areas because it is a controlled drug in our country. Therefore, those in rural areas in the country, cannot access palliative care because of distance and poverty. This should not be so because palliative care should be made accessible to everyone that needs it regardless of status or location.⁵

Apart from inaccessibility to all, there are several other barriers to the provision of effective palliative care in Nigeria. These challenges are due mostly to lack of Government policy, funding, lack of health care workers who are properly trained in palliative care, integration into the health care system, availability and acceptability of opioids especially morphine for proper pain management.⁶ According to a study carried out in Nigeria, 70% of the challenges facing palliative care practice in the country is due to lack of government policy, while 68% is attributed to lack of funding, 26% and 24% to manpower and transportation challenges, respectively.⁷

This article aims to review the practice of palliative care medicine in developing countries and the challenges in providing palliative care services in South-South Nigeria.

A Brief History of Palliative Care in Nigeria

Palliative Care was first introduced in Nigeria in 1993 by Mrs. Fatunmbi and Dr. Anne Merriman. All their efforts to set up palliative care services in the country proved abortive which led to Dr. Merriman moving to Uganda to establish the hospice Uganda.⁵ Palliative care was formally re-introduced to the Nigerian government policymakers and general public in 2003 through the Palliative Care Initiative of Nigeria (PCIN) now known as Center for Palliative Care, Nigeria (CPCN). It is located at the University College Hospital (UCH), Ibadan.⁸

Dr. Anne Merriman facilitated the inauguration of the Hospice and Palliative Care Association of Nigeria (HPCAN) together with the national association founding fathers and also provided the seed grant for the take-off of the association in 2007. The HPCAN in 2008 submitted a proposal for the establishment of Palliative Care Units in all the tertiary health institutions in Nigeria. As a result of this initiative, palliative care services have been established in at least 5 out of the 6 geopolitical zones and in about 15 tertiary health institutions in Nigeria.⁵ The palliative care unit of the University of Port Harcourt Teaching Hospital became the first palliative care service available in South-South Nigeria. The unit started providing services in June 2011 and it is a registered member of the Hospice and Palliative care association of Nigeria (HPCAN). There are various models for palliative care delivery and they include day-care support, palliative care outpatient clinic, inpatient care and Home-Based Care (HBC). The Palliative care unit of our hospital



offers Home-based care, out-patient clinic, in-patient services, and bereavement support.

The Challenges of Providing Palliative Care Services in South-South Nigeria The Burden of Life-Limiting Illnesses

Nigeria is divided into six geopolitical zones with 774 local government areas and an estimated population of about 200 million.⁹ It has a high burden of people living with life-limiting illnesses with about 100,000 new cancer cases occurring every year and 41,000 cancer-related deaths recorded in 2018. Apart from South Africa and India, Nigeria is the next country with the largest number of people living with HIV/AIDS.^{9,10} There are other life-limiting illnesses like sickle cell disease, chronic renal failure, diabetes, etc that also require palliative care.

The University of Port-Harcourt Teaching Hospital is located in the South-South geopolitical zone of the country. The Palliative Care Unit in the hospital comprises of about ten members. These numbers cannot effectively offer services to these large populations of patients with life limiting-illnesses. We, therefore, offer services to mostly cancer patients. Even with this, there is still an overwhelming large number of patients in need of palliative care within and outside the hospital. Home visit is an important component in the management of patient with life limiting illnesses. Due to few personnel and difficulty in transportation of the team, we can only offer home visit to very few patients. Currently, the unit is the only centre that offers Palliative Care Service in Rivers and Bayelsa States and we are

frequently called to see patients in other hospitals within these States.

Financial Burden Of The Disease

In Nigeria, where more than half of the people earn less than one dollar a day, it is practically impossible for the people to afford the cost of treating life limiting-illnesses.^{5,11} Therefore, most of our patients do not come to the hospital and when they come, cannot afford the basic treatment. Our Palliative Care Unit is inundating with patients that cannot afford their treatment and even basic pain medication. This is because our source of health care financing is mostly “out of pocket” for the majority of people with only about four percent of the population covered by the National Health Insurance Scheme (NHIS).⁵ Even though the NHIS coverage is low, patients with life limiting-illnesses like cancers still pay out of pocket for their treatment because these diseases are not covered by the scheme. As a result, the financial burden of cancer treatment on patients is very high in Nigeria because it is mostly borne by the patient, their relations and well-wishers.⁵

We found out that the estimated cost of managing one breast cancer patient in our center in 2019 was roughly one million, nine hundred thousand naira (\$4,983.6) excluding bed fees, feeding, and transportation which is lower than the lifetime costs of breast cancer per patient in the US (\$20 000-100 000).¹² The difference in the cost of treating might be due to the fact that the estimated treatment of breast cancer in our hospital is not a lifetime cost but the cost of the initial treatment of the breast

cancer. The breakdown of the cost of initial treatment of breast cancer in our hospital is as follows: chemotherapy – six hundred and twelve thousand naira (\$1,605), Surgery – three hundred and twenty thousand naira (\$839), Radiotherapy – six hundred thousand naira (\$1,573.7), Investigations:(laboratory/ blood work)- forty- eighty thousand naira (\$125.9), computerized tomography (CT scan) – one hundred and eighty thousand naira (\$472) and Ancillary- blood transfusion, drugs – one hundred and fifty thousand naira (\$393.4). There is no radiotherapy unit in the South-South region of Nigeria. Most of our patients need to travel to other states for radiotherapy and this results in additional cost from transportation and accommodation.

One of the reasons for the high financial burden of cancer treatment which unfortunately is preventable is the late presentation of most cancer patients to the hospital for treatment in developing countries. It is stated that in Nigeria, about 60–70% of patients with cancer present late.⁸ By the time of presentation, the cancer cells had spread to other organs resulting in complications. This can be prevented if the diagnosis is made early and treatment commenced immediately. Early diagnosis is possible if people have access to cancer screening centers. Cancer screening is expensive and most of our people cannot afford the cost. Even, when patients present early, treatment is delayed because of financial constraints. The heavy financial burden of cancer treatment results in many patients not accessing care or not completing their treatment. The effect on their family

members ranges from school dropouts, starvation to bankruptcy.¹³ Our challenge therefore, is how to ensure that our patients do not drop out of treatment due to financial constraints. Most time the unit sources for funds from external sources or contributions are made by the members to make sure our patients complete their treatments.

Poor Funding

Despite the great burden of life-limiting illnesses in Nigeria, there is insufficient political priority and funding amongst donor agencies and governments.¹

The average annual national budget is low and with many competing priorities; the funding of most tertiary health institutions is very small. Palliative care, therefore, is not included in most hospital's annual budget. More so, palliative care does not directly generate funds for the hospital. As a result, the basic things that are needed by the unit to provide services for our patients are not available.¹⁴ Most of our patients are indigent and have no means of financial support. Consequently, the staffs of the Palliative Care Unit of our hospital mostly bear the financial burden of those that cannot afford to access care through individual contributions. The unit tries to reach them at home and provide at least pain medication especially morphine.

Lack of Trained Personnel

Most health services in developing countries like Nigeria are designed for the prevention, diagnosis, and treatment of diseases. They were not intended to provide services for those with life-limiting illnesses and at the end-of-life.¹⁵ Therefore, those with life-

limiting or terminal illnesses and their families go through a lot of stress because health professionals treating them are not adequately trained or prepared to help them manage their stress. These health care providers often regard these patients as bed-blockers and will always be quick to discharge them from the hospital with no regard for how they and their families will cope.¹⁶ This is because the health care system and health facilities are not equipped with certain simple features that can help to meet the needs of those with life limiting-illnesses, most especially those with end-of-life needs. These needs include spiritual needs, family support, legal support where needed, and bereavement support to the family.^{5,17}

In Nigeria, 4.6 million people need palliative care with very few palliative care specialists.¹⁸ The insufficient Palliative care specialist is because palliative care is not recognized as an area of specialization for health professionals in the country and it is not taught as an undergraduate course in most of the tertiary institutions. However, it is currently being taught to medical students in very few Colleges of Medicine and a postgraduate diploma in one or two tertiary institutions in the country.¹⁹

Most of those involved in providing palliative care services in the country especially in our unit have no formal training and those that have received any form of training is by self-effort.²⁰ In a study done among palliative care providers, it was found that 47% have formal training in palliative care while 53% have had ad-hoc training post-basic. As a result, there are many gaps in their knowledge even as

palliative care providers.^{7,8,15,21}

Therefore, one of the major challenges is educating and training many health care professionals in Nigeria that are interested in providing palliative care services to those with life-limiting illnesses.^{10,22} This will not only provide well-trained professionals that can provide palliative care but will also provide the critical mass of specialist in palliative care that will help in establishing training centers in the country. Currently, in the south-south region of Nigeria, we do not have any formally trained palliative care specialist.

Lack of Knowledge About Palliative Care by Health Workers

In Nigeria, like most developing countries palliative care practice still faces some resistance as most specialties mount territorial protections. This is because most of the health care providers have insufficient knowledge concerning the interdisciplinary nature of the palliative care team, components of palliative care and the benefits of these services to the patients and their families. According to a study carried out among healthcare workers in Rivers state south-south Nigeria, 40.4% of the respondents believed that nurses only should be the ones to provide palliative care services and 28% believed the doctors should, while less than half of the respondents were aware of the multidisciplinary facet of palliative care. Most respondents (83.3%) believed that palliative care was indicated for the terminally ill patients, while few (25.4% and 17.5%) knew that patients with dementia

and diabetes mellitus, respectively should also benefit from palliative care services and some believed that everybody should benefit from palliative care²³

Lack of Palliative Care knowledge was also demonstrated in a study done by Onyeka¹⁰, in which over 71% of nurses in a tertiary institution perceived palliative care to be solely for the control of pain. A similar study done among doctors and nurses in a tertiary center found gaps in the knowledge of these healthcare providers which needed to be improved.²⁴ This, therefore, buttress the fact that there is an urgent need for continuing medical education for healthcare providers and more importantly the integration of this emerging branch of medicine into the curricula of the health training institutions. In our centre, most of the health workers refer patient for palliative care at the point of death. This is because most of them associate Palliative Care with end-of-life services. Therefore, patients are referred very late that they are not able to benefit from the end-of-life management as a result of their moribund state.

Poor Pain Management

The burden of symptoms amongst cancer patients is enormous with very few patients being able to access quality palliative care services. One of the most common symptoms experienced by a patient with a life-limiting illnesses is a pain, especially at the terminal stage. It is opined that more than 70% of those with advanced cancer or AIDS experience severe pain.²⁵

Pain in palliative care is multidimensional:

physical, psychological and spiritual pain. All the different dimensions must be handled to provide holistic treatment for the patient. The gold standard in the management of advance pain in patients with life-limiting illnesses is opioid especially oral morphine. Although, WHO had stated that all patient has the right to be pain-free and should be given morphine, this is not the experience in our center.^{4,5}

Most patients with life-limiting illnesses die in pain even in our hospital. The reason for this is mostly because most of our doctors are reluctant to prescribe morphine because of fear of addiction, supposed deadly side effects and diversion of the drug. Even when morphine is prescribed, the patient does not receive adequate pain management because of a gap in knowledge among health care providers and even among some of the health workers involved in providing palliative care on the right prescription of oral morphine for those with pain. According to a review of the prescription patterns of oral morphine solution over 6 months in a tertiary hospital in south-west Nigeria, only 1.1% of all prescriptions conformed to international guidelines of oral morphine prescription that emphasized dosage by the mouth, at four hourly intervals with a double dose at bedtime with prophylactic use of laxatives.²⁶ Currently, there is an improvement in the availability of opioid especially oral morphine in Nigeria although there is still the problem of distribution and bureaucracy.⁵

Communication Issues

One of the challenges in providing effective palliative care in our region is

communication. The difficulties in this area are due to several reasons. These include the fact that discussing an imminent death is a taboo and anyone that discloses such is regarded by the recipient as someone that desires their death. Consequently, most of the health workers shy away from this task and therefore, our patients with a terminal illness and their families are not given the full picture of the diagnosis and the prognosis. Also, most of the health workers lack the skill required to break bad news and are therefore afraid of doing more harm to the patient. As a result of these, the palliative care unit is left most often with the task of breaking bad news to the patient and their family without support from our other colleagues. These difficulties in communication became a challenge in providing palliative care. This is because the patient and their relations see the palliative care team as bearers of bad news and those that bring death wishes and finds it difficult to embrace the care that the team can provide for them. More so, these patients and their families do not understand the diagnosis and prognosis of the disease, therefore, they will not be receptive to the services available for them from the palliative care unit.

Cultural Issues

The Culture of a people impact their everyday life and affects how they interpret illness and interact with the health facilities especially as regard end-of-life issues. It also affects how health care providers views the end of life issues. The culture of a people is also affected by their religion. In Nigeria, we have mostly Christians, Muslims, and traditional worshipers. Cultural attitudes and behaviors,

therefore are significant barriers to the development and implementation of palliative care in Nigeria.

In our culture, it is a taboo to die young and sicknesses especially life-limiting illnesses are attributed to spiritual forces.⁸ Our patients seek to find out from native doctors and prayer houses the cause and cure for these sicknesses before presenting to the hospital. This mostly results in late presentation and most often at the point of death of the patient.

Also, our culture does not recognize the fact that some diseases may not have a cure. The fact that many cancer patients die even after receiving conventional western medical treatment discourages others from seeking western medicine. They prefer to resort to Complementary and Alternative Medicine (CAM) treatments, prayers, or faith to obtain healing.⁸

In most of our cultures, it is an abomination for certain cadre of people to die outside their home. It becomes imperative for palliative care to be provided for such a group in their homes. In our culture, you cannot discuss the property of a person while he is still alive. This is why most of our patients do not write a will because it means that they are preparing to die. Therefore, Healthcare professionals especially those involved in palliative care need to be culturally aware, acquire cultural knowledge, develop cultural sensitivity and demonstrate cultural competency in their practice.⁷



Conclusion

Palliative care in Nigeria, especially in the South-South region of the country, is still at the infantile stage and therefore there is the need for concerted efforts of both the local and international palliative care movements to help scale-up the provision of adequate palliative care that will be accessible to all that require it in this part of the country. This can be achieved by making and implementing health policies that support the integration of palliative care into the health system of the nation; changes in legislation and regulation that inappropriately restrict access to opioid medications for individuals with life-limiting-illnesses, most especially education and training of health professionals involved in palliative care and grants to help equip the units with basic things that are needed to effectively provide palliative care services.

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