

Palliative Care in Enugu, Nigeria: Challenges to a New Practice

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ABSTRACT

Everyone, young and old, male and female, rich and poor, should have access to excellent care during the course of a serious illness and at the end of life. Therefore, a denial of such care becomes an infringement of the individual's human rights. Because of the efforts of pioneers in this field of Medicine in Africa and beyond, both living and immortalized, we can now say that palliative care in the African context is affordable and achievable. In this article, some of the challenges faced in setting up and running a new palliative care practice in an emerging and developing economy are examined.

Key words: Challenges, New practice, Palliative care

INTRODUCTION

Palliative care involves the physical, emotional, practical, and spiritual aspects of the patient's suffering in the course of the illness.^[1] The aim of this article is to present a view of the challenges encountered by us as we established the Pain and Palliative Care Unit of our hospital and to give suggestions and recommendations to leaders and policymakers in emerging and developing economies around the world on how best to encourage and promote the field of palliative care.

Canadian physician Balfour Mount, a pioneer in the Canadian hospice movement, first coined the term "palliative care."^[2] The World Health Organization (WHO) defines palliative care as: "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by

means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual."^[3]

The hospice movement and modern-day palliative care is credited to Dame Cicely Saunders who started it in 1967. She was first a nurse, then a social worker, and finally trained and qualified to be a doctor.^[4] Several models of palliative care approaches exist in emerging and developing economies today. They include home care type, hospital unit, the day-care model, hospital support team model, and the nursing home model. One model in Africa, the free-standing inpatient hospice, was developed to respond to the needs of people with cancer and eventually was broadened to include people living with HIV, e.g., Hospice Uganda. Another example is the hospice developed primarily in response to the HIV epidemic, e.g., TASO, Uganda.

Palliative care was formally 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), located at the University College Hospital (UCH), Ibadan. Prior to this time, a few private-owned and missionary hospices existed in obscurity in the country. In 2007, CPCN launched its day-care hospice within the UCH.

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Our Pain and Palliative Care Unit, established in September 2008 as part of the Multidisciplinary Oncology Centre of the University of Nigeria Teaching Hospital (UNTH), Ituku-Ozalla, Enugu, is located in the South-Eastern region of Nigeria which is home to the Igbo tribe. A team consisting of one consultant physician anesthetist and some nurses from the multidisciplinary oncology unit began services with a pain clinic and inpatient rounds that later involved other tertiary medical institutions. In the course of practice, we have encountered the following challenges:

THE CANCER AND HIV BURDEN

Presently, the burden of terminal illness is increasing worldwide due to the rise in the prevalence of cancer, HIV/AIDS and increasing proportion of the elderly among us. In addition, there is increasing urbanization, industrialization, and westernization of dietary and other sociobehavioural attitudes in most developing countries.^[5] In Africa alone, it is estimated that about 2.5 million people die annually from HIV/AIDS, while more than 0.5 million die from cancer. Nigeria, the most populous country in Africa with a population of 140 million (as in 2006), is currently has the third largest number of people living with HIV/AIDS, after South Africa and India.^[6] The HIV/AIDS adult prevalence rate in Nigeria is 3.6%.^[7] Approximately 100,000 new cases of cancer occur in Nigeria annually.^[8] In our practice, we are overwhelmed by the large numbers of patients needing palliative care and are frequently called to see patients in other tertiary institutions and other hospitals within our region.

LATE PRESENTATION AND LATE DIAGNOSIS

Another challenge to the practice is the late presentation of patients, when the disease has already metastasized, leading to late diagnosis. In many developing countries, patients often present with far advanced malignant disease, of whom up to 80% of people with cancer may be incurable at diagnosis.^[9] In Nigeria, 60–70% of patients with cancer present late.^[10] This is mainly due to the belief that many patients have concerns regarding the origin of their conditions. A lot of our patients attribute their cancer as due to spiritual forces.^[11] Also, because many cancer patients die even after receiving conventional western medical treatment, other cancer patients are discouraged from seeking western medicine, and therefore resort to complementary and alternative medicine (CAM) treatments, prayers, or faith to obtain healing. These methods may be used in isolation or may be combined with western biomedicine. Use of traditional remedies and herbs

(generally called complementary and alternative medicine) has been known to influence patient presentation and follow-up visits after initial treatment. This is because of the expectation many of these patients have about CAM treating or curing their cancer.^[11] In one study of HIV/AIDS patients needing palliative care, the influence of traditional healers was seen in about 80% of patients who sought their advice, leading to delayed clinic presentation and medical intervention.^[1] For this reason, some palliative care systems have incorporated traditional healers in their education programs in order to gain community acceptance and facilitate palliative care delivery.^[1]

NOVEL SUBSPECIALTY OF MEDICINE AND NONINCLUSION IN THE EXISTING HEALTH STRUCTURE IN THE COUNTRY

Palliative care is a relatively new subspecialty of medicine in this part of the world and for this reason is yet to be included in the existing health structure of many developing nations. The combination of a lack of trained professionals in this area and an ever-increasing patient load makes it imperative that it should be incorporated into the healthcare structure, especially as it has been shown to improve patient outcomes.^[12] In 2006, the Nigerian government took the first step in addressing the numerous palliative care needs of the citizenry by launching the National Consultative Committee on Cancer Control, within which there is a Palliative Care subcommittee. However, a leaf should be borrowed from the Ugandan government that has prioritized palliative care, making it accessible to the population of 22 million people.^[9]

ABSENCE FROM MEDICAL UNDERGRADUATE AND POSTGRADUATE CURRICULA

Palliative medicine is of great relevance in the field of medical education through its emphasis on such issues as meticulous attention to complex symptom control, whole-patient care, interdisciplinary team approach, enhanced communication skills, support programs for the bereaved and the many ethical concerns relevant to the end-of-life care.^[13] Because many lack formal training, authorities in the field agree that health professionals should be trained in the field as well as its incorporation into undergraduate curricula. In a survey of 228 pediatric oncologists from the USA, Canada, and the UK, respondents reported a lack of formal courses in pediatric palliative care.^[14] Ninety-two percent admitted that they had learned to apply palliative principles of care by trial and error in clinical practice. A

few admitted to learning by observing colleagues or other role models during their fellowship training and residency. There is presently no formal palliative medicine being taught in any Nigerian institutions of higher learning, but informal trainings and advocacy through workshops have been going on. Members of the Society for the Study of Pain, Nigeria (SSPN) are currently promoting the review of curricula in tertiary institutions^[15] which includes pain management while the Hospice and Palliative Care Association of Nigeria (HPCAN) is striving to ensure that palliative care eventually has a place in medical education throughout the Nigerian nation. Undergraduate students should be encouraged to be around dying people, so that they can learn how to develop a meaningful connection through reflective practice, and how to develop a humane approach toward their patients.^[16] This can be achieved by producing a generically evaluated and evaluated core undergraduate curriculum for medical and nursing undergraduates together with postgraduate and continuing professional education,^[17] in the form of end-of-life lectures in the undergraduate curricula, institution of residency training in palliative care, and the organization of training workshops, seminars, and conferences for healthcare professionals in the field.

INTERFERENCE OF CULTURAL BELIEFS CONCERNING SICKNESS AND DEATH AND INFORMATION CENSORSHIP

One major hindrance in rendering palliative care in our environment is the taboo of speaking of an impending death. There seems to be a culture of “death denial” among patients, their relatives, and healthcare professionals. The Igbos of Eastern Nigeria have a culture of celebrating life (“Ndu bu isi”), while despising and fearing death, especially if the dead was younger than 60 years.^[18] Where death is accepted, Africans prefer natural prolongation of the dying process and want to be at home so that they can make their peace, say farewell, and give final instructions to immediate relatives.^[19] Hence one finds that many terminally ill keep away from medical treatment for fear of hospitalization. This belief is similar to other Eastern countries. For example, in China, talking about the possibility of death in front of a sick person is often viewed as cursing them or hastening death.^[20] There is a form of professional or cultural taboos against open communication about death among physicians.^[21] Healthcare professionals in many cases censor their information giving to patients in an attempt to protect them from potentially hurtful, sad, or bad news. However emerging evidence from recent studies show that although truth hurts, deception hurts even more.^[22] In our

practice, patients with terminal illness are not given the full picture about their diagnosis and prognosis. On the few occasions, they have been educated about their illness and the possible outcomes, some patients have rejected the idea that they have cancer. This practice of trying to shield the patients from the reality of their situation is common in most developing countries and contrasts sharply with the trend in some developed nations that practice the core principles of palliative care which are as follows: (1) open disclosure and honesty; (2) patients’ autonomy through their active participation in decision making; and (3) open expression of feelings and concerns.^[23]

UNDERDEVELOPED PAIN MANAGEMENT

Although there are no national prevalence statistics about pain in Nigeria,^[24] we find that many of our cancer patients have pain and this constitutes a major health problem. Effective pain management and control is a very vital facet of palliative care as unrelieved pain affects both quality of life and the will to live among these patients. Poorly managed pain will lead to poor quality of palliative care provided. There are difficulties encountered in diagnosis of pain in our environment which is a result of shortage of specialist oncologists, pain specialists, and pain clinics. Most times, cancer pain is treated by nonspecialists. Eighty percent of cancer patients are known to have pain in the terminal phase of their disease while 25% of HIV/AIDS patients also have pain in the course of their illness.^[25] In many developing countries like Nigeria, the prevalence of pain at time of cancer diagnosis is between 50% and 75%.^[26] A study of terminal cancer patients in Kenya and the UK found that Africans’ main concern was for pain control and analgesia, while for the UK patients, the major concern was emotional pain.^[1] Uganda is only the third African country to have made morphine available and affordable to its patient population.^[9] The several challenges facing effective pain relief in our practice are similar to those of other developing nations and include drug availability, lack of referrals, fears of misuse of potent narcotics/under-prescribing, lack of public awareness (healthcare workers, policymakers/administrators, the public), cultural and religious beliefs,^[24] shortage of financial resources, limitations of healthcare delivery systems and personnel, absence of national policies on cancer pain relief and palliative care, and legal restrictions on the use and availability of opioid analgesics.

MYTHS ABOUT OPIOID USE

Despite the fact that no literature currently exists on the

knowledge and attitude of Nigerian healthcare professionals toward the use of morphine and other opioids, we have observed that many are afraid to prescribe strong opioids (unpublished data). Their counterparts in North-Eastern Portugal have been noted to have several false beliefs about morphine side effects, addiction issues, and legal constraints.^[27] Fear of euthanasia, the health professional's beliefs and prejudices, and lack of knowledge are some of the obstacles to effective pain management for dying patients in resource-rich countries.^[28] In Korea, this has been seen to prevent effective cancer pain management.^[29,30] Physical dependence and tolerance may occur in patients who take opioids over a long period, but psychological dependence is extremely rare. Therefore, the risk of dependence should not be a factor in deciding whether or not to administer opioids to a cancer patient with pain.^[31] Morphine, given in increasing amounts, is safe and should be administered until the pain is relieved without producing an "overdose," as long as the side effects are tolerated. Morphine has no standard dose. The ideal dose is the one that relieves the pain.^[31]

UNAVAILABILITY OF OPIOIDS, PROBLEMS OF OPIOID REGULATION, COMPOUNDING AND OPIOID COST

The International Narcotics Control Board (INCB) believes that opioids are underused in the treatment of pain, especially cancer pain, and has called on governments to reevaluate their needs.^[31] Opioid importation costs in developing nations has been known to be 10 times the cost in the developed world.^[32] Some countries, because of the fear of opioid diversion and abuse, have enacted laws that make the procurement of opioids for medical use difficult. In several European countries, excessive regulation of opioids has been shown to contribute significantly to effective cancer pain management.^[33] In Nigeria, the Federal Ministry of Health is the sole importer of opioids while the National Agency for Food and Drug Administration and Control (NAFDAC) is the regulatory body but both have major bureaucratic complexities between them in this regard.^[24] At present, there are no parenteral preparations of morphine and pethidine available for use in the country. A ban placed on the compounding of oral preparations of drugs in our hospital several years ago was only lifted recently to allow for the preparation of liquid oral morphine used in the treatment of cancer pain in our patients. Nigerian policymakers should work out national guidelines pertaining to the availability, reasonable cost, prescription, and safe storage of opioids as this would ensure proper treatment of pain in patients needing pain relief.

RESOURCE-POOR SETTING

We lack specialist palliative care physicians for now. Our patients are nursed in large open wards with little privacy. In addition, there is no pipeline oxygen in the wards and patients in need of oxygen have to make do with oxygen delivered from cylinders. The nurse staffing is insufficient to meet all the needs of the many patients we care for. And while our palliative care remains largely hospital based, home-based care suffers tremendously as our palliative care team visits fewer patients. However, the Hospice Africa Uganda (HAU) experience is a success story that has shown that palliative care is possible even in resource-poor settings. This most advanced hospice program in Africa was able to surmount the barriers of manpower insufficiency (through volunteer training and monthly palliative care "roadside" clinics),^[34] legal restriction of opioids, and doctor-only diagnosis of terminal cancer or AIDS to produce a highly successful palliative care program today. The International Association for Hospice and Palliative Care (IAHPC), encourages every country to develop a palliative care model based on its own resources and conditions, while at the same time adapting hospice and palliative care experiences in other countries to suit its needs.^[35]

RADIOTHERAPY UNIT WOES

Radiotherapy (RT) is a vital part of multidisciplinary cancer management. It functions effectively in the palliation of bone pain, brain metastasis, and other symptoms' control in advanced or recurrent cancers. It is known that many low- and middle-income countries have limited access to RT, with 22 African and Asian countries having no form of RT service.^[36] About 50–80% of breast cancers in these countries are advanced at presentation and inoperable, therefore requiring treatment by RT.^[36] As in 2008, there were only 5 RT centers, 60 qualified pathologists, and 20 radiation oncologists serving the entire Nigerian nation. No patient has ever received RT from our institution. The team for RT should include radiation oncologists, medical physicists, radiation technologists, and radiation nurses. These professionals are meant to work through an integrated process to plan and deliver RT to cancer patients.^[37] At present, we have only three trained personnel, two consultant radiotherapists, and a radiographer. Cobalt units or linear accelerators may be used to deliver radiation, with the latter requiring continuous maintenance to ensure the continuous provision of a safe beam of radiation. A linear accelerator supplied to our hospital by VAMED Engineering Nigeria Limited in 2007 is in the process of being installed.

CANCER REGISTRY PROBLEMS (POOR RECORDKEEPING)

The absence of proper detailed cancer data is a major factor militating against cancer management in the country. Because cancer is a significant health problem in Nigeria and many developing nations, the collection of relevant information on cancer is of great necessity. Cancer registries provide accurate and extensive information about all cancers within a given population. Because cancer registries are meant to follow up patients up till death, they are important in monitoring cancer survival in a given population.^[5] Prior to now, there had not been a comprehensive cancer registry and recordkeeping in our institution had been poor. This situation was further compounded by failure of many cancer patients to seek orthodox medical help. In order to reverse this trend, the Institute of Human Virology Nigeria (IHVN) in April of 2009 organized training in Cancer Registration and Epidemiology. The purpose was to provide an opportunity for training of cancer registry personnel, network them, and reestablishing the National Headquarters of Cancer Registries so as to facilitate the collection of an up-to-date cancer incidence record. Such data can be used in a wide variety of areas of cancer control ranging from etiological research to healthcare planning and patient care. With data obtained through such research, the link between certain cancers and environmental factors and occupational exposures can be ascertained.^[5]

CONCLUSION

WHO's "little cost, big effect" measures which include education, increased drug availability, and changes in government policy^[9] should be adopted. Advocacy and public education are essential to creating awareness, breaking the fallacy of cure versus palliation in our communities, and raising the profile of palliative care.^[3,38] Research in palliative care should be encouraged as this would help in the identification of palliative care needs in the country and subsequently improve standard of practice of the profession as well as care of the terminally ill. Policymakers in the government should ensure that palliative care is integrated into the nation's health system, with some budget allocated for that purpose. Medical practitioners should be encouraged to incorporate this field of medicine into their routine practice, following the Uganda example where palliative care for patients with AIDS and cancer has been made a priority in its National Health Plan.^[3] Finally, palliative care medications such as opioids should be included in the essential drug list.

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