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Palliative Care: The Nigerian Perspective

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Abstract

Palliative care is an area of healthcare that focuses on relieving and preventing the suffering of patients. It utilizes a multidisciplinary team approach to ensure a “holistic” care of the patient. It is a relatively new concept in medicine and the Nigerian experience has not been widely studied. Despite its introduction into the nation over two decades ago, it still faces a lot of challenges in terms of integration into the health care system, implementation and governmental policy. With increasing longevity, urbanization, high prevalence of HIV/AIDS and chronic diseases including malignancies, there will be an increasing number of Nigerians requiring palliative care.

Keywords: palliative care, holistic approach, Nigeria

1. Introduction

When treatment for cure is not possible and the only option is palliative, the patient is said to be terminally ill [3]. In a patient that is terminally ill, the estimated life expectancy is less than or equal to 6 months, under the assumption that the disease will run its natural course [3, 2].

Care of the terminally ill, infirm and elderly individuals has been a key part of many societies. Since the fourth century, Rest house, Sarai, Sanatorium and Hot springs, were developed as special places to attend to their needs [1–3]. It has been realized that the needs of terminally ill patients were not met by the then prevailing specialist or non-specialist health system. Terminal care was not as elaborate as it is performed today. It was initially carried out by nuns and other charitable organizations. Palliative care was not included in the existing health care system of those days. Individuals and groups with a Christian commitment have been important in establishing pioneering palliative care programs in many places, and again have usually seen in education the best hope of contributing to care for the dying. From the 1980s rapid progress was made in developing palliative care as a discipline in the health care delivery.

The word “palliative” in Latin means “caring” [1]. This is the total care of patients whose conditions do not respond to curative treatment. It relieves suffering and improves the quality of life for both patients and families throughout an illness experience, not just at the end of life. Sometimes palliative care and hospice care are confused, and they have similar goals. However, hospice care is specifically for terminally ill patients while palliative care is more general and offered to patients whose conditions are not necessarily terminal. Palliative care begins when illness is diagnosed and continues regardless of whether the patient receives treatment directed at the disease.

According to the World Health Organization (WHO), palliative care is defined as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psycho-social and spiritual” [1]. It is the comprehensive care of the individual whose is considered as having a body, soul, spirit and family members who require support. It is also about living as well as dying with dignity. It is a good practice for the physician to refer his patients who require palliative care to access such care. This will not necessarily diminish our status as health care providers. Palliative care is often referred to as end-of-life care, but 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. Most health services are designed for prevention, diagnosis and treatment of diseases, but there is a huge need for ongoing care those who do not get better.

Palliative care is usually an organized care, which can be given, in a hospital setting, hospice or in the home of the patients. Resource constraints in developing countries, direct the site of care. Home-based care is cheap and acceptable to the family and the patient, and can offer care that respects cultural practice and removes the need for family attendance at hospital [4, 5].

The approach to patients care is “holistic,” meaning that the patient is viewed as a person with physical, psychological, social and cultural gifts and needs which are special to that person [4]. The holistic approach looks after problems in four groups:

1. Physical: symptoms
2. Psychological: worries, fears, sadness, anger
3. Social: family needs, issues of food, work, housing and relationships
4. Spiritual: questions of meaning of life and death, the need to be at peace

It thus involves a multi-professional team approach. This is a team of professionals who are committed to working together to provide the patient and her family comprehensive care. Palliative care is “a calling.” The team must be prepared to offer selfless service without expecting reward and function as a family, showing love for each other and those who visit them—patients, relations, and visitors. Recognize that every member of the team is precious. Volunteers are expected to attend a course to allow them see the depth of hospice care. Confidentiality and ethical issues are a priority.

The pioneering works of Dame Cicely Saunders in the United Kingdom and of Anne Merriman in Africa drew the attention of the medical community and the public to the evolution of palliative care in the 1960s [1, 6]. In the African continent, Uganda, South Africa and Kenya are among the earliest to develop palliative care. In November 2002, in Cape Town South Africa, the African palliative care association (APCA) was formed [7]. It was registered in 2003 and opened its headquarters in Uganda in 2005 as a non-governmental organization (NGO), with a regional mandate to promote and scale-up culturally appropriate and affordable palliative care for people with progressive, life-threatening and life-limiting illness. Palliative care is still at a developmental stage in Nigeria despite decades of its introduction by Mrs. Fatunmbi and Dr. Anne Merriman in Nigeria in 1993 [8]. The year 2003 was when palliative care was properly introduced to the Nigerian government, policy-makers and general public. It is now known as the Center for Palliative Care Nigeria

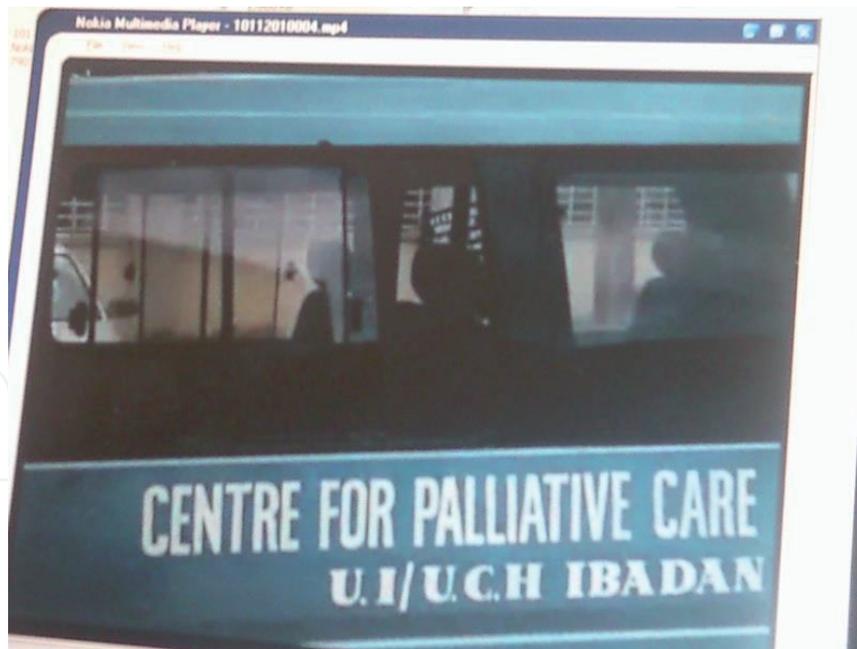


Figure 1.
The center for palliative care at the University College Hospital (UCH), Ibadan. It provides day care and outreach services for home-based care.

(CPCN), located at the University College Hospital (UCH), Ibadan [8]. In 2007, CPCN launched its day-care hospice within the UCH as shown in **Figure 1**. A pain and palliative care unit was established in 2008 at the multidisciplinary oncology center of the University of Nigeria in Enugu, South-eastern Nigeria [9].

2. Palliative care in Nigeria

Nigeria is the most populous country in Africa. It has an estimated population of 160–180 million scattered around six geopolitical zones and 774 local government areas (LGA). The country has the third largest number of people living with HIV/AIDS after South Africa and India [10]. Approximately 100,000 new cases of cancer occur annually in Nigeria and thus there are large numbers of patients needing palliative care [9]. There is a gradual erosion of the hitherto extended family support and patients get isolated both at home and in the hospitals. The life expectancy is lower than in most of the developed countries with low gross domestic product (GDP). The annual national budget for health is a ridiculous 1.5–3%, oscillating whenever there is a change in Government. Medical services are provided through out-pocket payment or user fees. Health insurance is provided mainly to the 1% of the population employed in the civil service. Thus, provision of adequate health services goes to the highest bidder.

Palliative care is still new to the country owing to the fact that it is not included as an area of specialization for health professionals across the country. It is now currently offered as an undergraduate course at the College of Medicine, University of Ibadan and postgraduate diploma in a privately owned University in Ilorin, Kwara state [8].

In 2006, Dr. Oyebola Folaju, became the first specialist in palliative medicine in Nigeria following a postgraduate training in palliative medicine at the famous University of Cape Town, South Africa [8]. He pioneered palliative medicine in Nigeria and became the first full-time pain and palliative care physician by establishing the first pain and palliative medicine department at the Federal Medical

Centre Abeokuta, Nigeria. This was the first hospital-based palliative medicine services and the beginning of integrating chronic pain management, palliative and end-of-life care, into an acute care hospital in the country [8]. Through his efforts the country today can boast of more than 15 similar facilities in Nigeria making use of their local institutional policies to move forward. Most families prefer the home-based care. It provides familiar environment, opportunity to attend to siblings, access to family and friends and privacy are advantages. This is performed in conjunction with family, primary care team and specialist within the hospital or hospice.

Despite the prescriptions of the WHO in 2002 and its re-emphasize at the 2004 WHO general assembly that palliative care should be integrated into all nations' health care system, several African countries including Nigeria are yet to approve it as a policy. This situation had contributed significantly to the slow level of palliative care development in Nigeria, as the palliative care practitioners have no access to the nation health budget.

3. Palliative care-challenges in Nigeria

The problems militating against the provision of palliative care in Nigeria can be broadly classified into the following:

1. Poor awareness, knowledge and skills
2. Inability to discuss cancer diagnosis and management with patients
3. Lack of trained professionals
4. Lack of resources
5. Problems associated with availability of medications including oral opioids
6. Lack of government policy/priority

3.1 Poor awareness

In Nigeria, 60–70% of patients present to health care facilities with advanced disease, when treatment for cure is virtually impossible [11–13]. Patients are referred late for care and by the time they get to the palliative care center, most of them were already down. The reasons for late presentation include late recognition of initial symptoms due to lack of knowledge, search for alternate treatment and cure, inappropriate advice, poverty and fear of hospitals. Such patients at presentation are at an advanced stage of the disease with several distressing symptoms requiring palliative care.

Many victims of terminal diseases have died as a result of lack of knowledge about palliative care. Statistical data are grossly inadequate and unreliable in Nigeria. The absence of a population-based cancer registry in the country has hampered policy formulation and planning [7]. In a study about knowledge of palliative among medical interns in a tertiary health institution in north-west Nigeria by Nnadi and Singh in 2016, the interns showed inadequate knowledge about palliative care. Among those that reported knowledge about palliative care, many held misconceptions regarding the signs and symptoms and the disease conditions

that require palliative care [14]. The sources of knowledge about palliative care were mainly from school lectures and healthcare personnel. This underscores the need to include palliative care in the school curriculum both at the undergraduate and postgraduate levels. The residency training is a critical window of opportunity for training about good end-of-life care for dying patients and their relatives [14].

A similar study in Ibadan, Nigeria in 2002 on the knowledge and attitudes of terminally ill patients and their relatives to palliative care and hospice services in Nigeria, showed gross lack of knowledge about palliative care in our community, but a positive attitude towards palliative and hospice services [4].

There is also poor knowledge of palliative care among health care workers and reluctance by doctors in Nigeria to prescribe morphine where it is available because of fear of addiction. Morphine remains a controlled drug in Nigeria and in some other countries because of fear of diversion of prescribed morphine. Knowledge gap have also been identified even among health care practitioners that provide palliative care in terms of their understanding of the goals that palliative care seeks to achieve [15]. Financial constraint is given as the major physical factor that prevents the patients from acquiring even their pain medications.

3.2 Spiritual consciousness

Nigeria is a multi-ethnic, multicultural and multi-religious country. Islam is the major religion in the north, while Christianity predominates in the south. In between there is an amalgamation of Christianity and Islamic religious practices. Despite the practice of these major religions, traditional religious worship reign supreme. The influence of traditional religion permeates the life of an average Nigerian. Religion influences our action, our decision, inspirations, goals, motivations, principles and our contentment. Thus traditional medicine practitioners are well patronized and are usually the first port of call especially in the rural setting. Orthodox medical care is still viewed with suspicion even among the educated class.

There is a belief in a diabolical interference existent in almost all illnesses in Nigeria. Accusing fingers are usually pointed to an “envious” neighbor or mate as being responsible even for the slightest form of ill health. The rising trend of the Pentecostal religious movement has not helped matters. It poses a significant means of spiritual or faith-based healing among Nigerians. The health implication is that among many Nigerian Christians, faith healing ministers have taken the place of conventional therapists for their health problems. These confirm that the belief in the efficacy of African traditional healing and church spiritual healing is so strong among Nigerians that they rely on these methods irrespective of some experiences of failures. Thus, many individuals who are unfortunate to be befallen by terminal diseases, attribute their predicaments to witchcraft and spiritual attacks [9].

Many Nigerians don't believe in making their wills until the final moment because of a strong belief in dying by natural means and for fear of being killed by disaffected family members. Thus speaking of impending death is seen as a taboo. This presents a major obstacle in rendering palliative care in our environment. There seems to be a culture of “death denial” among patients, their relatives, and healthcare professionals [16]. Thus having an eye-to-eyeball discussion of impending death with a terminally ill patient may result in stigmatization of the doctor. Suspicion, abuse, rejection of therapy and even signing against medical advice may follow. The patient may then gravitate from one health care facility to another in a futile attempt to get cure. Spiritual homes, faith-based healing centers and herbal remedies would be profusely patronized at a great cost to the patient. When eventually death comes, the family and dependents are left impoverished and unable to foot the burial expenses. Our people hardly accept the reality of failed treatment

or death. Their firm belief is that doctors treat and make patients well. The doctor must continue to offer hope even when reality is to the contrary. Where death is accepted, many would want to be at home so that they can make their peace, say farewell, and give final instructions to immediate relatives [9]. Hence one finds that many terminally ill keep away from medical treatment for fear of hospitalization.

3.3 Psycho-social problems

The model approach to palliative care in the western world differs significantly from the African setting. Palliative care needs in African countries include home and respite care, pain and symptom control, financial, emotional and spiritual support, and also food, shelter, legal help, and school fees. Management of disease-related pain in patients with hunger pains highlights the importance of adapting palliative care models from developing countries to African settings. Traditions dictate appropriate models and places of care: sick people might be removed from villages to avoid risk to the community, or returned from the hospital to the community to avoid dangers of overcrowded wards and toxic drugs from developed countries. Access to effective cancer pain relief is hampered by poor social conditions, criminality and urban violence.

There is some social stigma associated with disease entities. Stigma can prevent patients with HIV/AIDS from referring themselves to palliative care.

Many Nigerians would not want to be associated with terminal diseases. They believe that if the public comes to know about their state of health, it would bring dishonor to them and family [9]. The stigmatization that is being shown to victims of deadly diseases in Nigeria, affects the socio-economic progress of the country, as the sufferers probably miss work, and are unemployed or stop-working early. In the mainly Islamic northern part of the country, cultural norms such as Purdah restrictions can prevent women from seeking health care outside the home for themselves. Cultural norms such as traditional practices and use of herbs also discourage the use of more effective modern medical practices. This underscores the relevance of social support in coping with adversity among patients of diverse ethnic origin. In Nigeria, the perception of ill-health is much more complex than the mainstream biomedical approach. The concept of well-being and ill-health is much more holistic, involving the body, the mind and in some instances the supernatural. Thus, superstition, ignorance and cultural practices tend to affect the health-seeking behavior of our people. In our setting, the multidisciplinary palliative care team should include spiritual care givers, family members and friends so as to meet the entire needs of the patient.

3.4 Governmental policy

Palliative care in Nigeria is still at a developmental stage. Initially the attitude of the Nigerian government towards palliative care was weak and non-committal due to lack of advocacy. Through the efforts of the Hospice and palliative care association of Nigeria (HPCAN), palliative care services have appreciated in almost all the six geopolitical zones of the country. The association has liaised with the federal ministry of health to establish palliative care units in all tertiary health institutions in the country. In addition, the federal government of Nigeria has designated six federal hospitals as oncology centers of excellence.

Despite all these, there remain a lot of challenges in implementation of effective palliative care services in Nigeria. Many cancer treatment centers are located mainly in the urban setting. Thus patients in the rural areas cannot access them due to distance barriers and poverty. Many radiotherapy centers in the country

lack functional machines. Even when the machines are available, there is dearth of adequate manpower to maintain them. Morphine, the gold standard medication for pain relief in cancer patients, remains a controlled drug in Nigeria. Due to fear of misuse and abuse, the government is yet to decentralize the distribution of opioids in the country. The Federal Ministry of Health remains the sole importer of opioids, while the National Agency for Food and Drug Administration and Control (NAFDAC) monitors the distribution. The result is that morphine is not readily available to those that need it [8, 9]. Some health workers consequently, have resorted to less effective but more available alternative medications such as Tramadol and Pentazocine, for pain relief.

The problems facing the implementation of effective palliative care in Nigeria cannot be excised from the overall prevailing socio-economic condition in the country. Poverty, ignorance, insecurity, poor funding of healthcare, inadequate manpower and poor policy formulation and implementation constitute obstacles to effective good health care delivery.

4. The way forwards

There is a paucity of information on hospice and palliative care provision in Nigeria and only a weak evidence base upon which to build policy and practice development. Overall, services remain scattered and piecemeal in the country, and coverage is poor. Pioneer workers in palliative care established small models of care to act as foci for education initiatives, so that palliative care can spread to wider areas. They saw in education, as the best hope of contributing care for the dying. It would be wishful thinking to assume that age old beliefs could be eradicated in a twinkle of the eye, but education will create awareness, remove taboos, and modify some attitudes and behaviors. The best way to do this is by incorporating palliative care into the medical undergraduate curriculum and residency training program. Public enlightenment through the print and electronic media will further create awareness; eliminate the stigma associated with terminal illness and regard dying as a normal process. It will provide psycho-social, spiritual and bereavement support for family members. Patients with terminal diseases should be encouraged to seek palliative care at a place best suitable for them. Outreach services for home-based care should be encouraged and adequately funded.

We need advocacy to present our case to the general populace. Government alone cannot shoulder the responsibility involved in implementing an effective palliative care. The private sector of the economy, corporate bodies, religious and traditional leaders need to be carried along. The government needs to address its policy on availability and distribution of morphine in the country. Palliative care champions in Nigeria are working to demonstrate how morphine access can be appropriately integrated into healthcare systems. Through political advocacy and public awareness, the necessity of integrated palliative care can be better understood.

5. Conclusion

Both Specialist and integrated palliative care have important role in Nigeria as the “extended family” system is fast breaking down. Grafting palliative care into existing networks of home-based care is feasible and must be adapted to Nigerian needs. Government policy and support, private-public partnership initiative, collaboration with partners is essential to establish palliative care education and

service in Nigeria. Palliative care is all about love, support, care, effective control of pain and distressing symptoms in times of special needs.

Acknowledgements

We acknowledge the previous author cited in the text.

Conflict of interest

Nil declared.

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