

National Policy and Strategic Plan for Hospice and Palliative Care

2021



Federal Ministry of Health, Abuja



National Policy and Strategic Plan for Hospice and Palliative Care in Nigeria 2021

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FOREWORD

Hospice and Palliative Care (HPC) is an approach that improves the quality of life of patients and their families facing problems associated with life-threatening/limiting illnesses, which can be physical, psychosocial, and spiritual in nature. It offers support to help patients and their families cope during the patient's illness and in the period of bereavement.

Access to good quality palliative and end of life care is a basic human right and a vital component of a comprehensive health care delivery system for both children and adults. In recognition of this, the World Health Organization (WHO) in 2014 called on all member states to develop and implement policies to ensure evidence-based, effective, and equitable HPC is integrated into national health services.

To date, HPC remains inaccessible to many Nigerians with the majority in need dying with no access to good quality HPC at their end of life. Where available, HPC service is largely restricted to a few tertiary institutions and virtually absent at secondary and primary care levels. In addition, there is poor awareness on HPC among health workers and the general public.

This policy document is a product of an all-encompassing contribution from all relevant stakeholders in the field of Hospice and Palliative Care in Nigeria. It is expected to create public awareness and educate heath workers on HPC, galvanise a focused support for action on development/implementation of a good quality HPC service in Nigeria, provide guidelines on identification of patients with HPC needs/standards and quality of care HPC givers are expected to provide for patients and institutionalise HPC at all levels of the Nigerian health system towards achieving a universal health coverage/access to HPC for all Nigerians.

I am confident that the adoption of this policy by all tiers of the Nigerian health system will enhance the delivery of a comprehensive healthcare package to the Nigerian people. I therefore strongly recommend its adoption by all tiers of government in Nigeria.

Dr. E. Osagie Ehanire, MD, FWACS

Honourable Minister of Health

June 2021

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I also wish to thank the Staff of Federal Ministry of Health especially Pharmacists from Department of Food and Drugs and National Cancer Control Program led by Dr Okpapo Okpikpi for their efforts in actualising this much needed policy document.

I encourage all tiers of government in Nigeria to implement this policy in their health institutions in order to improve on comprehensive health service delivery to the teaming Nigerians in need of it.

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ACRONYMS/ABBREVIATIONS

APCA African Palliative Care Association

CMEs Catastrophic Mass Events

COVID-19 Coronavirus Disease 2019

CSOs Civil Society Organizations

FBO Faith Base Organisation

FMoH Federal Ministry of Health

HIV/AIDS Human Immunodeficiency Virus Infection and Acquired Immune

Deficiency Syndrome

HPC Hospice and Palliative Care

HPCAN Hospice & Palliative Care Association of Nigeria

IAHPC International Association for Hospice and Palliative Care

IDPs Internally Displaced Persons

LGAHA Local Government Area Health Administration

NCDs Non-Communicable Diseases

NGOs Non-Governmental Organizations

POS Palliative Outcome Scale

SHS Serious Health-related Suffering

SMoH State Ministry of Health

SSA Sub-Saharan Africa

SSPN Society for the Study of Pain, Nigeria

TCAM Traditional, Complementary and Alternative Medicine

WHO World Health Organization

WHPCA World Hospice Palliative Care Alliance

DEFINITIONS

Catastrophic An event or situation involving or causing sudden great damage or

suffering. Catastrophic health expenditure is when a household's spending for health exceeds 40% of income leading to

suffering/impoverishment.

Epidemic A widespread occurrence of an infectious disease in a community

at a particular time.

Hospice and Palliative

Care Policy

illness:

Team

This is an intention and broad guideline which elaborates government's goals and actions when it comes to implementation of Hospice and Palliative Care services across all levels of the health

system.

Life-limiting illness Life-limiting illness is a term used to describe an incurable

condition that will shorten a person's life, though they may continue

to live active lives for many years.

Life-threatening These are usually chronic incurable diseases which have the effect

of considerably limiting a person's life expectancy.

Multi-disciplinary A group of health care workers who are members of different

professions (e.g. Physicians, Nurses, Pharmacists, Social workers,

etc) each providing specific services to the patient.

Pandemic An epidemic that has spread over multiple countries or continents

at the same time.

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CHAPTER ONE: BACKGROUND

1.1 Introduction

International Association for Hospice and Palliative Care (IAHPC), defines Hospice and Palliative Care (HPC) as the active holistic care of individuals across all ages with serious health-related suffering due to severe illness and especially of those near the end of life. Hospice and Palliative Care focuses on a continuum of care from diagnosis till patient's death and bereavement. It addresses all domains that may cause suffering including end-of-life care, loss, grief, and bereavement. It encompasses the support system for patients and their families when they face life-threatening illnesses. The overall goal is the achievement of the best possible quality of life for both patients and their families, relieving pain and helping people to cope with death. There is now an overwhelming body of evidence that for patients with serious illness, HPC can improve patient outcomes, including symptom control and quality of life, and caregiver outcomes, such as reduced stress and dysfunctional grief.²

Hospice and Palliative Care is an emerging and fast-growing specialised discipline in Nigeria. Although it is now a key component of a comprehensive cancer control programme in the country, ³ HPC is not yet a subsystem of a broader Hospice and Palliative Care strategy that includes other health conditions besides cancer. Despite its existence in the country for more than 15 years, and the recent increases in HPC service availability in Nigeria, major challenges remain in making these services accessible to all Nigerians in need.^{4,5,6} It remains underdeveloped, limited in scope and practice and the geographical coverage remains concentrated in the urban and peri-urban locales, often out of reach for a sizeable proportion of the population who reside in rural areas. Also, the majority of the existing services are located mainly in few isolated tertiary health institutions in the country, with some participation from a few Non-Governmental Organizations (NGOs) and Faith-Based Organizations (FBOs). Hospice and Palliative Care is virtually non-existent at the secondary and primary healthcare levels. There is no comprehensive integration into the different levels of the health system structure using HPC teams as recommended by the World Health Organization (WHO). This arrangement obviously cannot support equitable access to all those in need. Furthermore, there is hitherto, no National Hospice and Palliative Care policy and clinical practice guidelines. This is probably because until recently, non-communicable diseases (NCDs) including cancers have been accorded low priority among the health and welfare problems facing Nigerians.

In 2014, the first-ever global resolution on Hospice and Palliative Care, World Health Assembly resolution WHA67.19⁸, called upon WHO and member states to improve access to Hospice and Palliative Care as a core component of health systems, with an emphasis on primary health care and community/home-based care. The World body recommends that all countries of the world develop comprehensive HPC policies and programs with a public health approach, integrated into their existing health system and tailored to the needs and prevailing cultural attitudes and practices of each country. To give effect to this, the world body emphasizes the essential ingredients of education, drug availability and effective government policy, as strategies to achieve full integration. Several other resolutions are in support of HPC into national health systems in Africa. Among these are:

- i. The consensus statement for HPC integration into Health systems in Africa, entitled "Palliative Care for Africa" issued on the occasion of the First African Ministers of Health Session on palliative care held on 17th September 2013 in Johannesburg; and
- ii. The most recent Consensus statement for strengthening palliative care as a component of comprehensive care throughout the life course in Africa "The Kampala Declaration 2016" issued on the occasion of the second African Ministers of Health session on Palliative Care at the 5th International African Palliative Care Conference in Kampala, Uganda⁹.

According to WHO, a comprehensive service delivery system needs to include preventive, curative, palliative, rehabilitative and health promotion services. ¹⁰ It further emphasizes the need for these services to be accessible and well-coordinated, of good quality, covering all people for a defined population with continuity of care and patient-centeredness. It does appear, therefore, that the present healthcare package in Nigeria may not fully address the healthcare goals of a substantial proportion of the populace. The lack of universal access to HPC in Nigeria, no doubt, leads to considerable suffering for many patients and their families. The need for a National Hospice and Palliative Care Policy in Nigeria has become pressing to provide clear directions, strategies and plans of action to ensure equitable, accessible, affordable and efficient HPC for all in need of the services in Nigeria.

1.2 SITUATIONAL ANALYSIS

Hospice and Palliative Care is a relatively new concept in Nigeria and is still in its early stage of development. Like in most developing countries, HPC services remain underdeveloped or lacking in most parts of the country.

Currently, the majority of HPC services in the country are located in tertiary health institutions and exist in most cases as hospital-based clinical units to provide some form of inpatient care and outpatient clinics through consultations with the relevant disciplines. There are no dedicated inpatient HPC beds and no government-owned stand-alone Hospice Care services.

Hospice and Palliative Care exists as autonomous clinical departments in a few tertiary hospitals in Nigeria, (e.g University College Hospital Ibadan, Oyo State and Federal Medical centre Abeokuta, Ogun State). There is still no adequate community awareness about HPC in the country.

The government has shown commitment towards the development of HPC in the country in the last decade. It was included as goal No 10 in the National Cancer Control Plan (2007-2013),²⁷ as well as the National guidelines for HIV and AIDS treatment and care in adolescents and adults. It is also one of the thematic areas of the current National Cancer Control Plan (2018-2022).³ There is a need for formal recognition of HPC as a speciality to encourage healthcare workers to consider careers in this field in Nigeria.

Good pain control is an integral component of effective HPC. Opioid analgesics are considered essential medicines by the World Health Organization, ²⁸ but access to them is still severely limited in Nigeria. There is low availability of opioid drugs for pain relief in the country due to policy obstacles, and bureaucratic bottlenecks associated with the procurement process.

Therefore, in the search for practical, meaningful, and attainable objectives to improve care for patients with cancer and other life-threatening diseases in a resource-limited setting like Nigeria, securing access to essential pain medicines is a top priority. This is to ensure that such patients do not have to suffer unnecessarily. This situation has recently improved with the implementation of the "Pain-Free Hospital Initiative" project of the American Cancer Society (ACS), which is a collaboration between the Federal Ministry of Health and the American Cancer Society. By this collaboration, the ACS supports the implementation in many hospitals, to integrate pain treatment into service delivery by providing education for patients and staff, raising motivation and awareness, measuring and documenting pain levels, and improving essential medicine supply. Until recently there were only 9 radiotherapy centres, out of which only two or three worked at any given time and just about 30 radiation oncologists in Nigeria.²⁹ However, recent efforts by the government to improve the situation has seen more radiotherapy centres coming on board to offer services to patients but this is still a far cry from what is required to serve the need of our population. It is believed that the country requires a minimum of 200 radiotherapy machines to treat the estimated over two million cancer patients. Consequently, radiotherapy services are still not generally available in the public health system. Where radiotherapy services are available; access is limited by cost and location. Chemotherapy services are either not readily available or were available, the high cost of the drugs prevent most patients from taking advantage of modern regimens. Hence physicians have limited access to treatments that offer the prospect of prolonged survival for cancer patients. In addition, there are very few specialist medical and surgical oncologists available in the country. ²⁹ Currently, societies such as the Nigerian Cancer Society, Society for the Study of Pain in Nigeria (SSPN), Hospice and Palliative Care Association of Nigeria (HPCAN), and the few HPC services are available, as well as patient advocacy groups that are active in promoting HPC in the broad action on cancer control and prevention. The Federal Ministry of Health is also supportive of the development through the creation of an HPC desk and a dedicated HPC officer in the Federal Ministry of Health, and the National Agency for Food, Drug Administration and Control (NAFDAC). Efforts by committed individuals since the 90s have also resulted in the establishment of few HPC centres in Nigeria. These pioneers/leaders in collaboration with other concerned stakeholders in the Health Industry came together to inaugurate the National Association called Hospice and Palliative Care Association of Nigeria (HPCAN) in 2007. This association has been in the vanguard of providing awareness, education and coordination of Palliative Care services in Nigeria since its inauguration. All these efforts need to be sustained and improved upon.

Emerging Palliative Care Sites -> 2016



Figure 1: Mapping of Current Hospice and Palliative Care services location in Nigeria

1.3 Education

Most healthcare professionals have limited knowledge and expertise in caring for patients with life-threatening diseases and their families and addressing the physical, emotional, and spiritual issues related to dying and death. However, there have been several ad hoc training aimed at empowering established healthcare practitioners to be able to render HPC to patients. A few healthcare providers (Doctors and Nurses) have taken it upon themselves to travel outside the country to acquire postgraduate education in HPC medicine; a rather expensive endeavour with huge personal sacrifices. The introduction of HPC into undergraduate training of health care professionals has been described as a necessary step in the development of a formal system of education. However, this is far from being achieved in many health care training institutions in Nigeria. A recent review of medical students' curriculum at the Universities of Ibadan and Ilorin has now incorporated pain and palliative care as a core module in the undergraduate curriculum. Also, the Senate of the University of Ilorin recently approved the proposal to commence postgraduate diploma training in palliative medicine to further equip established healthcare professionals to render specialized palliative care, but the programme is yet to take off.

1.4 VISION, MISSION, GOALS AND OBJECTIVES

1.4.1 Vision

Access to good quality Hospice and Palliative Care for all Nigerians of all ages with a life-threatening illness and their families/caregivers

1.4.2 Mission Statement

To provide culturally appropriate, affordable and accessible patient-centred evidence-based Hospice and Palliative Care to meet the needs of all Nigerians with life-threatening illnesses and their families/caregivers, through a well-coordinated multidisciplinary approach involving all relevant stakeholders integrated into the healthcare service delivery at all levels (primary, secondary and tertiary).

1.4.3 Goals

- 1. To promote Hospice and Palliative Care as an integral part of a comprehensive package of health care and humanitarian response to serious health-related suffering made available to all Nigerians in need (children, adolescents and adults).
- 2. To achieve maximum coverage by ensuring that Hospice and Palliative Care services are integrated into service delivery, especially at primary, secondary and tertiary care levels.
- 3. To secure sources of funding for Hospice and Palliative Care services and ensure regular availability of medications for adequate pain management.

1.4.4 Objectives

The principal objectives of this policy document are:

- 1. To ensure the provision of good quality and equitable Hospice and Palliative Care services in Nigeria.
- 2. To ensure that Hospice and Palliative Care becomes an integral component of health care service delivery towards actualising universal health coverage.
- 3. To widen the coverage of Hospice and Palliative Care across all levels of health care.
- 4. To ensure proper and adequate training of health care professionals on Hospice and Palliative care.
- 5. To promote culturally appropriate Hospice and Palliative Care services to all patients in Nigeria.

1.5 POLICY STATEMENT

This policy document is intended to improve the quality of life of patients with life-threatening illnesses and their families/caregivers through collaboration with Hospice and Palliative Care experts, international and national organizations, relevant associations, Civil Society Organizations and Non-Governmental Organizations.

1.6 SCOPE OF THE POLICY

This policy document was developed in line with the priority areas of action of the Nigeria National Cancer Control Plan 2018-2022. It covers the entire spectrum of the levels of care from primary to quaternary levels of prevention up to death and bereavement. The document addresses the following 8 thematic areas

- 1. Leadership and Governance
- 2. Service Delivery

- 3. Health Workforce
- 4. Medical Products, Drugs and Technology
- 5. Health Information and Palliative Care Research
- 6. Health (Hospice and Palliative) Care Financing
- 7. Ethical and Legal Considerations of Hospice and Palliative Care
- 8. Monitoring and Evaluation

1.7 POLICY DEVELOPMENT/REVIEW PROCESS

This National Hospice and Palliative Care Policy was the product of widespread consultations with, and participation of Hospice and Palliative Care experts at the Federal Ministry of Health and Tertiary Health institutions in the country who developed a zero draft. The draft was reviewed by the National Technical Working Group on Cancer Control and prevention in Nigeria to produce the second draft. The draft document was further reviewed by larger/relevant stakeholders to produce the final draft which was signed into policy by the Honourable Minister of Health. This policy will be reviewed every five years in line with new advances in Hospice and Palliative Care services.

CHAPTER TWO: IMPLEMENTATION FRAMEWORK

2.1 LEADERSHIP AND GOVERNANCE

The Nigerian national health care system is built based on the three-tier system at the Federal, State and Local Government levels. Each tier of government has its health priority agenda and is at liberty to develop its health care system at its own pace. Integration of Hospice and Palliative Care services into the existing health system at all levels of government is important in ensuring both accessibility and sustainability of services. To achieve this integration, there should be appropriate government policies that ensure adequate medicines availability, education of health care workers and the general public, and implementation of culturally appropriate and accessible Hospice and Palliative Care services at all levels of healthcare.

2.1.1 Strategic Actions:

The roles and responsibilities of each tier of government shall be as follows:

Federal Ministry of Health (FMoH)

The Federal Ministry of Health through the Department of Hospital Services shall:

- 1. Provide national leadership and coordinate efforts of states and local governments to ensure synergy and minimize duplication of services.
- 2. Enhance collaboration and linkages between all Governments' Hospice and Palliative Care activities
- 3. Support Hospice and Palliative Care curriculum development and implementation for all undergraduate and postgraduate health professionals' courses.
- 4. Monitor, supervise and evaluate the implementation of approved Hospice and Palliative Care services/programmes, through data collection, feedback, and service development.
- 5. Build research capacity for Hospice and Palliative Care to promote evidence-based practice.
- 6. Monitor the routine reviews of existing policies to include Hospice and Palliative Care to ensure implementation of an integrated HPC service policy.
- 7. Work with states and local governments to assess and manage Hospice and Palliative Care issues related to special populations (e.g., refugees, internally displaced persons, persons in correctional facilities, etc).
- 8. Analyse and guide on ethical and legal issues relating to service delivery

State Ministry of Health (SMoH)

- 1. Monitoring adherence to standards and guidelines on HPC at General Hospitals.
- 2. Raising awareness about HPC services in their states.
- 3. Ensure data collection and feedback mechanism to the National level.
- 4. To champion the establishment of HPC in their health care institutions in collaboration with Federal Health institutions.

Local Government Health Administration (LGAHA)

- 1. Local Government Health Administration shall ensure the integration of Hospice and Palliative Care in the delivery of Primary Healthcare Services.
- 2. Create awareness on Hospice and Palliative Care services.
- 3. Ensure data collection and feedback mechanism to the SMoH.

2.2 SERVICE DELIVERY

2.2.1 Conditions Requiring Hospice and Palliative Care

Hospice and Palliative Care is a comprehensive care and support to improve the quality of life and relieve the suffering of patients facing life-threatening illnesses and their families. These are illnesses associated with significant long-term physical, psychosocial and spiritual suffering.

Although Hospice and Palliative Care are most often associated with cancer, clinicians are beginning to accept the growing body of evidence that patients with other non-malignant chronic progressive and incurable diseases also require HPC. It can be applied to any life-threatening disease. The diseases may include cancer, HIV/AIDS, organ failures, cerebrovascular disease, neurodegenerative disorders, sickle cell disease, chronic respiratory diseases and diseases of older people such as dementia/Alzheimer's disease, congenital anomalies, metabolic and chromosomal disorders, cerebral palsy etc.

2.2.2 Access to Comprehensive Hospice and Palliative Care for all Nigerians

Access to good quality palliative and end-of-life care and support is a basic human right and a vital component of a comprehensive healthcare delivery system for both children and adults. The World Health Organization (WHO) in 2014, called on member states to develop and implement policies to ensure evidence-based, effective, and equitable HPC is integrated into national health services.⁸ To date, HPC remains inaccessible to many Nigerians, with a majority of the population dying with no access to appropriate care at the end of life.

Strategic Actions:

- 1. Hospice and Palliative Care shall be made available, accessible and affordable to all children, adolescents and adults with life-threatening illnesses in Nigeria, regardless of social status, religion, cultural affiliation or place of domicile, and implemented by the three tiers of government, private sector and other implementing partners.
- 2. The HPC service delivery shall be tailored to meet the patients' physical, psychosocial and spiritual needs and the prevailing cultural attitudes and practices.
- 3. HPC shall be provided through a multidisciplinary team approach and integrated into the National Health care system at all levels of health service delivery. This is because the trajectory of life-threatening illnesses is complex, and the burden of treatment often involves several care transitions leading to extensive and varying support needs as the patient's condition advances to the terminal stage.
- 4. The service shall be available to these patients in the context of a continuum of care from the time of diagnosis, adapting to the increasing needs of the patients and their

- families as the disease progresses into the terminal stage. The service should also provide support to families in their bereavement.
- 5. Government and relevant agencies shall ensure the implementation of this policy.
- 6. All primary health care centres shall have outpatient Hospice and Palliative Care services established. The HPC needs of all patients should be identified and efforts made to address them by primary health care providers trained in HPC.
- 7. All secondary and tertiary healthcare facilities in Nigeria shall have inpatient Hospice and Palliative Care consultation services which should be available to hospitalized patients with HPC needs. Consultation services should be provided by an interdisciplinary team, including (but not limited to) a physician, nurse, counsellor, and pharmacist. Clinical psychologists and spiritual services should be added to the team.
- 8. All healthcare facilities providing oncology care services shall have dedicated inpatient HPC beds, staffed with trained professionals. No oncology centre, hospice, or palliative care facility should exist without a well-developed multidisciplinary palliative care team.
- 9. Hospice and Palliative Care needs of all patients shall be addressed at a presentation by health professionals trained in HPC, using appropriate screening tools, especially when disease-modifying interventions are not available or when patients cannot receive active treatment with curative or life-prolonging intent.

2.3 HEALTH WORKFORCE

2.3.1 Health workforce requirement

The trajectory of care for patients with a life-threatening illness is often complex with various physical symptoms, complex psychosocial and spiritual issues and, in some cases, very significant co-morbidities. Hospice and Palliative Care is provided by a multidisciplinary care team consisting of experts from different healthcare disciplines, including Doctors, Nurses, Pharmacists, Physiotherapists, Clinical Psychologists, Social workers, volunteers, faith-based workers and other health care professionals. These are held together by continuous communication and teamwork, to address the multidimensional needs of patients including those of children with their different developmental stages and their families/caregivers.

Generally, HPC needs can be categorized into two: one that is more general and should be met by any primary health care system, and another that requires additional specialized services and should be met by specialised HPC service providers. In addition to the general needs, all members of the multidisciplinary team should be aware of the particular needs related to the specific life-threatening disease which may require intervention from specific members of the multi-disciplinary team.

2.3.2 Category of healthcare providers involved in palliative care and their roles

Physicians

Physicians play a crucial role in interdisciplinary Hospice and Palliative Care. They must be competent in general medicine, pain management and familiar with the principles of management of the patient's disease. Trained Specialist HPC physicians are needed as teachers, implementers, advisers and supervisors. They work alongside other specialities in a multi-disciplinary team to deliver specialized HPC for patients in need of the services. Their other roles include mentoring, service development in line with local, national, and WHO guidelines, education, and research.

Nurses

Nurses in the team typically have the greatest contact with the patient. The prolonged contact gives the nurse a unique opportunity to know the patient and the caregivers, to assess indepth what is happening and what is of importance to the patient, and to assist the patient to cope with the effects of advancing

Core members of the multidisciplinary team

- 1. Physician(s).
- 2. Nurses (for both in-patient care and community care).
- 3. Clinical Pharmacist.
- 4. Physiotherapist.
- 5. Clinical Psychologist (or visiting liaison psychiatrist).
- 6. Occupational Therapist.
- 7. Nutritionist.
- 8. Social Worker.
- 9. Music and/or Art Therapist.
- 10. Spiritual Care Providers.

disease. Their nursing expertise is required in providing physical and emotional care to the patient, symptom management, patient and family education, and ameliorating grief in the event of the loss of a patient.

Clinical Pharmacist

The pharmacist plays a significant role in promoting rational use and ensuring access to essential medicines for palliative care, as well as compounding of Opioids including paediatric formulations. S/he is required to work with other members of the healthcare team in resolving drug therapy problems of a patient (side effects, medication error, drug-drug interaction, adverse drug reaction etc) and also provide information on current dosage regimen, route of administration, indication and contraindication of the medicines.

Physiotherapist

Physiotherapy plays a vital role in rehabilitative services needed by patients facing life-limiting illnesses. It aims to maximise movement and function, were threatened by ageing, injury or disease. This is essential for optimal well-being and critical for optimal patient-centred care. Physiotherapy has been found to positively influence the quality of life of patients with life-limiting illnesses.

Social Workers and Psychologists/ Mental health professionals

Social workers and clinical psychologists attend to the psychosocial/counselling needs of patients and their families. Their primary role is to help the family and patient deal with the personal and social problems of illness and disability, as well as to provide support during the progression of the disease and the bereavement process if the patient is at the end of life. The assessment by social worker/psychologist may help in defining the patient's and family's needs

from a psychosocial perspective and helps anticipate problems within the family that may result from dysfunction and financial difficulties, particularly as the family begin planning for the future.

Spiritual Counsellors

As patients approach the end of life, they often begin to think about the meaning and purpose of life and feel the need to mend broken relationships by forgiving and being forgiven. Spiritual care providers give spiritual care, and may also advise and assist the care team to support the patients and their families. Spiritual counsellors need to be trained in end-of-life care and should be skilled and non-judgemental listeners, able to handle questions related to the meaning of life as may arise for patients and their families. The role of the spiritual counsellors is often one of listening, to facilitate recollection of the past and growing readiness for what lies ahead. They also often serve as confidants and sources of support for those with a religious tradition, organising religious rituals and sacraments that are meaningful to the patient.

Volunteers

The role of the volunteer within the palliative care team varies depending on the setting. They are included in Hospice and Palliative Care teams to assist healthcare professionals to provide services that will improve quality of life. Incorporating them in an HPC team brings in a dimension of community support. With the appropriate training and support, volunteers provide direct service to patients and families, help with administrative tasks, house chores or even work as counsellors.

Traditional Healers

The role of traditional medicine and traditional healers is well recognized but their inclusion in the HPC team depends on the accepted practice of the setting. In most settings, traditional healers do not usually become members of the HPC teams. However, some patients with chronic incurable diseases resort to some form of complementary or alternative therapy, either before or during their orthodox treatment. There is therefore a need for an open discourse between healthcare providers and traditional healers to coordinate their efforts to address the needs of patients and their families, sensitively and respectfully, taking into account the diverse cultures of communities and individuals.

Strategic Actions:

- 1. The relevant health care providers should be trained to prepare them for the challenges of providing palliative care services.
- 2. FMoH should work with the relevant regulatory bodies of training institutions to incorporate HPC in their curricula.
- 3. A programme of care for caregivers and families of patients should be integrated into the Hospice and Palliative Care services.
- **4.** Government shall provide for a regulatory framework to ensure proper monitoring of the efficacy, safety, and quality of traditional HPC services.

5. FMoH shall ensure the establishment of an HPC multi-disciplinary team in all health institutions.

2.3.3 Training

Hospice and Palliative Care is an emerging specialized discipline in Nigeria, and the growing demand for the service means that health professionals are expected to provide HPC as a core part of their practice. Education is a critical pillar for developing palliative care with a public health approach.⁸¹ A study done by Fadare et al⁸² identified gaps in the knowledge of healthcare workers in the area of HPC and recommended the need to improve their capacity.

Definite attempts need to be made to align the undergraduate and postgraduate training curricula and clinical placements of our healthcare professionals to enhance the theoretical learning and practical application suitable for the delivery of HPC.

Strategic Actions:

- 1. Government shall develop basic HPC training curricula for different healthcare professionals.
- 2. All healthcare professionals should be trained in basic HPC skills so that they can develop effective HPC knowledge and attitudes.

2.4 MEDICINES AND HEALTH PRODUCTS

2.4.1 Essential Medicines for Hospice and Palliative Care

The World Health Organization recommends that countries establish a National Drug Policy that ensures availability and accessibility of essential medicines, (particularly opioid analgesics for treating moderate to severe pain). Hospice and Palliative Care services need to cover not only opioids and other pain relief medicines, but rather a holistic approach to Hospice and Palliative Care and its integration into other care and support services like chemotherapy and radiotherapy. The essential equipment, patient supportive devices, technologies and supplies for HPC are contained in the September 2019 African Palliative Care Association's essential palliative care package for universal health coverage report.⁷⁴

Opioids

The WHO considers morphine as the 'Gold Standard' in the management of moderate to severe pain. Since pain is one of the most frequent and serious symptoms experienced by patients in need of Hospice and Palliative Care,⁶¹ Countries have an obligation under international law to ensure the availability of morphine and other opioids for medical purposes and to take steps to prevent non-medical use.

The main obstacles to effective pain relief in HPC in Nigeria are insufficient availability of opioids due to regulatory and policy obstacles, weak procurement systems and myths. A study has shown that 80% of patients with AIDS or cancer, and 67% of patients with cardiovascular disease or chronic obstructive pulmonary disease will experience moderate to severe pain at the end of their lives. Unfortunately, access to effective pain relief medicines is severely limited in most low- and middle-income countries, including Nigeria.²⁸

Strategic Actions:

- 1. The FMoH should ensure the sustained availability of morphine and other opioids for use by both public and private facilities providing HPC services in the country.
- 2. Every facility setting up HPC service must include measures to be able to guarantee the availability of the essential medicines for palliative care.
- 3. Government shall develop regulations and guidelines to address emerging issues on availability, accessibility and rational use of controlled medicines
- 4. The FMoH and other regulatory agencies shall enforce existing regulations for prescriptions and distribution of opioids in Nigeria to prevent non-medical use and diversion.
- 5. The Essential medicine lists for Nigeria shall be reviewed and updated to include the WHO essential HPC medicines lists for adults and children.
- 6. Facilities offering HPC should ensure the availability of equipment and consumables required for optimal services, including items like pressure-reducing mattresses, appropriate prostheses, opioid lockboxes, syringe drivers, colostomy bags, adult diapers etc.
- 7. Government shall ensure the review of National laws, legislation and existing policies to identify and promote opportunities to increase access to controlled medicines taking into consideration gender, human rights and administrative bottlenecks that may hinder access.

2.5 HEALTH INFORMATION AND PALLIATIVE CARE RESEARCH

Research is important in any area of science, health and medicine. This is particularly true for a new and evolving speciality like HPC. Without research, advances in the science of control of symptoms and quality of care will stagnate and HPC will cease to meet the future challenges/needs of patients with advanced life-threatening illnesses and their caregivers. Research is a key and vital component to the effectiveness of HPC implementation and integration. The current reality of HPC research in Nigeria, and generally in Africa, points to the fact that there is insufficient methodologically robust evidence-based information on the most effective and culturally appropriate HPC services.

There is a need to promote awareness within the health professionals, policymakers and the populace to avail the majority of patients of the benefits of HPC services.

This will encourage new findings, insights, understandings and treatments, and inform the delivery of effective and appropriate HPC services. The delivery of safe, effective HPC and ongoing quality improvement in service provision are critically dependent on reliable valid measurement of patient-relevant and clinically important data. There is therefore the need to build a strong evidence-based practice and generate empirical data to demonstrate that existing HPC services meet the needs and expectations of individual patients, in terms of relevance, quality of care, and cost-effectiveness. Research is also required to identify needs and priorities, reveal an understanding of specific social and cultural issues to guide policy formulation and clinical practice and produce lessons that can be replicated elsewhere on the continent. Furthermore, there is a need to audit the current palliative care services in the country to

identify successes and failures to ensure that evolving services serve the patients most effectively despite the constraints of limited resources.

Strategic Actions:

Government at various levels shall:

- 1. Support a comprehensive nationwide HPC needs assessment in collaboration with relevant stakeholders such as Hospice and Palliative Care Association of Nigeria (HPCAN), NGOs and other partners.
- 2. Ensure research and development to advance HPC through the provision of grants and other funding.
- 3. Engage in the development of research capacity on HPC through training of relevant professionals.

2.6 HEALTH (PALLIATIVE CARE) FINANCING

2.6.1 Funding for Hospice and Palliative Care Services

Cancer patients and other patients who require HPC services in Nigeria face significant financial challenges at various stages of care for their disease conditions for several reasons, including loss of income, costs of treatments, (medications, diagnostics, chemotherapy and radiotherapy), and costs of travel to treatment centres. This is compounded by poor coverage of these conditions by the National Health Insurance Scheme (NHIS). It is therefore important for collaboration between different tiers of government and implementing partners to develop sustainable financial strategies to finance HPC service provision in Nigeria.

Possible sources of funding/Support:

- 1. Government funding: All tiers of government should provide funding for HPC services at Health facilities within their purview.
- 2. Government shall ensure the inclusion of HPC services in NHIS.
- 3. Co-payment by the end-users of HPC services.
- 4. Fundraising and donations, legacies, subsidies, foundations, seed-funding etc
- 5. NGOs/CSOs

2.6.2 Awareness Creation

To increase the awareness of the importance of HPC in the public and facilitate the support of the public and NGOs, the government should enlist the support of media organisations, including TV, radio, internet (Facebook, Twitter etc.) and newspapers.

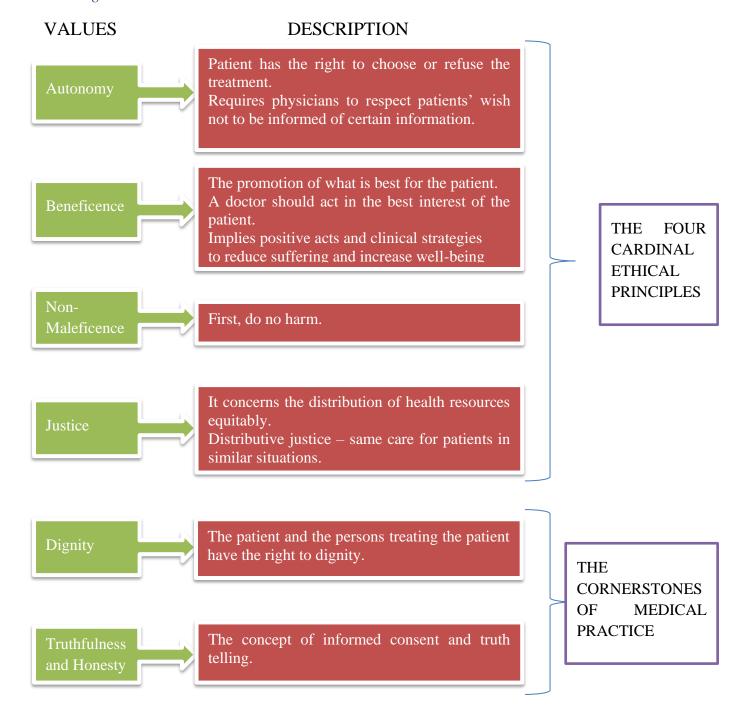
2.7 ETHICAL AND LEGAL CONSIDERATIONS OF HOSPICE AND PALLIATIVE CARE

2.7.1 Ethical aspects of HPC

Legal aspects of healthcare and human rights give fundamental protections to all and 'no one ought to harm another's life, health, liberty or possessions'⁸⁴ in the process of providing HPC services. The delivery of HPC and medical ethics should therefore be seen as complementary and the use of the two together should address deficits in care and maximize the protection and

satisfaction available to the vulnerable patients and family members. Care and support should balance the ethical principles in terms of protecting vulnerable patients, including children and ensure that services only provide benefits to the patient and family whilst causing them no harm.

Figure 2: The Six Values in Medical Ethics⁸⁵



Strategic Actions:

- 1. Hospice and Palliative Care experts and team members shall carry out their responsibilities in accordance with the six values of medical ethics.
- 2. Medical professionals should undertake research, trials, and scientific studies for the progress of HPC practice and the enhancement of the evidenced-base discipline. They shall carry out such activities legally and ethically, balancing the ethical principles in terms of protecting the vulnerable patient from harm and at the same time carrying out scientifically designed studies.
- 3. Rights and ethical considerations for the patient shall be observed as in the Nigeria National Patients' Bill of Rights and the United Nations Convention on the Rights of the Child.
- 4. When a child's wishes differ from those of the adult decision-maker, appropriate professional staff members shall be made available to assist the child.

CHAPTER THREE: STRATEGIES TO ACHIEVE KEY OBJECTIVES

Table 1: Strategies to Achieve Key Objectives

S/N	OBJECTIVES	STRATEGIES	RESPONSIBLE ORGANISATION
1.	To ensure the provision of quality and equitable HPC services in Nigeria towards achieving Universal Health Coverage.	the country.	FMoH, SMoH, LGAs, NHIS, Individual institutions, Other Implementing Partners
2.	To widen the coverage of HPC across all levels of health care.	Implement HPC policy at all levels of health care.	FMoH, SMoH, LGAs, Individual institutions, Implementing Partners
3.	To ensure proper and adequate training of health care professionals on HPC.	 i. Incorporate Hospice and Palliative Care into the training curriculum of undergraduate and postgraduate colleges. ii. Conduct regular training and retraining of all categories of health workers on HPC. 	FMoH, SMoH, NUC, Postgraduate Medical Colleges, Health Regulatory Bodies, FMoE, and Implementing Partners.
4	To promote culturally appropriate HPC services to all patients in Nigeria.	i. Integrate community/ faith-based organizations and TCAM in HPC services.	FMoH, SMoH, LGAs, Communities, FBOs, Individual institutions, Implementing Partners.

CHAPTER FOUR: MONITORING AND EVALUATION

4.1 PROCESS OF MONITORING AND EVALUATION

This would provide a framework for continuous assessment of the effectiveness of Hospice and Palliative Care services in the country. The Monitoring and Evaluation shall cover the following thematic areas:

- 1. Service Delivery
- 2. Health Workforce
- 3. Medicines and Health Products
- 4. Health Information, and Palliative Care Research
- 5. Clinical Auditing

Table 2: Monitoring and Evaluation Framework

S/N	ACTIVITY	STRATEGY	EXPECTED OUTCOME	RESPONSIBLE ORGANISATION
1.	Service delivery	Provision of hospice and palliative care services in all primary, secondary, and tertiary health facilities across the country.	Number of health facilities with functional HPC services at the three levels of health care	FMoH, SMoH, LGAs, Individual institutions, and other implementing partners.
2.	Capacity building of health workers	Training of various categories of health workers (doctors, nurses, pharmacists, technicians, and other health workers) on HPC.	Number of trained healthcare practitioners on HPC	FMoH, SMoH, LGAs, Individual institutions, Implementing Partners
3.	Medicines & Health products.	Provision of pain relief medicines and other support facilities. Establish and maintain a reliable supply chain for opioid medicines and health products necessary	Availability and accessibility of essential medicines for pain relief e.g. opioids and other support facilities	FMoH, SMoH, LGAs, Individual institutions, Implementing Partners

		for strengthening HPC services.		
4.	Health Information and HPC Research	Strengthening of HPC research and information management.	Published research work on HPC. Integration of palliative care service into the	FMoH, SMoH, LGAs, Individual institutions, Implementing
5.	Quality improvement and Clinical auditing of HPC services.	Regular auditing of HPC services for quality improvement.	NHMIS Improved quality of HPC services across the country	Partners FMoH, SMoH, LGAs, Individual institutions, Implementing Partners

ANNEXURES

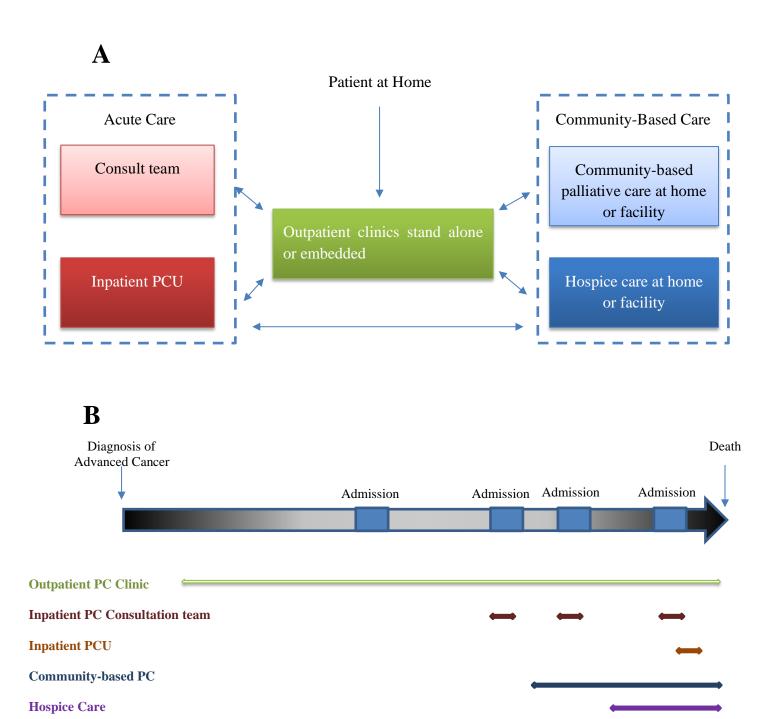


Figure 3: Clinical Models of Hospice and Palliative Care Delivery

A: Care anywhere B: Care anytime.

The arrows indicate the general time frame of patient engagement

Table 3: Description of Clinical Models of Palliative Care

CLINICAL MODELS	DESCRIPTION
Outpatient HPC	Represent the key point of entry for timely access to HPC in the disease trajectory. Care is offered for ambulatory patients at clinics. It can offer low-cost care to a large number of patients, and when coupled with an inpatient consultation service, is the best model if resources and start-up funding are limited.
	It requires relatively few resources, can serve a large number of patients, and represent the main setting for patients to be seen early along the disease trajectory.
	Care can be provided by a team comprising of a nurse, social worker and Doctor. Psychologists and faith workers may also perform important roles in some settings.
	Variants of outpatient HPC interventions include:
	Stand-alone clinics : HPC delivered by an interdisciplinary specialist Palliative Care Team.
	Embedded clinics: The HPC team and the primary care team share the same clinic space and see the same patients on the same day. HPC is delivered by an interdisciplinary specialist Palliative Care Team if it is a specialised clinic at a tertiary level hospital, or health care workers at the clinic if it is a primary health care clinic. Telehealth-based: Primary model of outpatient HPC service delivery, particularly for patients in rural areas where access to tertiary care is more challenging. Telehealth HPC may also be provided as an outreach to augment existing outpatient clinics. Clinicians may be able to provide education, counselling, and symptom monitoring in a cost-effective manner with the potential to improve adherence, increase hospice referrals and minimise acute care visits. Much of the available evidence currently supports stand-alone clinics delivered by an interdisciplinary specialised HPC team. 66 Enhanced Primary HPC: Primary HPC provided by nurse practitioners (instead of
	specialised HPC teams) in the oncology clinic. This model of care without specialised palliative care is not supported by available evidence.

Inpatient HPC consultation services

This may exist in two variants:

Hospital-based HPC teams: This is a hospital-based consultative service provided by a specialised multidisciplinary inpatient HPC consultation team. The patient remains the responsibility of the admitting and treating team, but are supported by the HPC team. The HPC team, consisting of a physician, a nurse practitioner, a social worker, and a Spiritual Care Provider and/or psychosocial professionals, typically have daily rounds with hospitalized patients. The focus usually is on symptom management and care planning. Continuity of care after discharge can be provided by outpatient or community-based HPC.

Inpatient HPC consultation services represent the backbone of palliative care. Studies have shown that hospital-based HPC consultations can reduce hospital costs.^{68,69}

Day Care HPC Services. This may be another variant of Inpatient HPC consultation services. Day-care HPC programs provide physical, psychological, social, and spiritual support, as well as counselling and medical services for patients and respite and bereavement care for caregivers. The programs may be offered to assist patients and families in coping with the illness. Daycare can also play an important social role (e.g. providing food and companionship) or rehabilitative function (e.g. physiotherapy or occupational therapy), and skills training. The service may be independent or attached to another service (e.g. a hospital or a clinic), but more often, are attached to an inpatient hospice unit.

Daycare palliative care service providers are often supported by volunteers.

Acute Hospice and Palliative Care Unit (AHPCU)

AHPCUs are dedicated inpatient units where the interdisciplinary HPC teams assume primary responsibility to deliver comprehensive care that addresses the physical, emotional, and spiritual domains of suffering for patients in severe distress. It is for patients with the highest level of distress and complexity. This is similar to the concept of intensive care units where medically complex patients receive life-sustaining therapies from highly specialized teams. Apart from conventional acute care, the teams often conduct complex interventions, such as rapid analgesic titration/rotation for intractable pain, palliative sedation for refractory agitated delirium, and facilitating difficult goals-of-care discussions and discharge planning.

Community-Based Hospice and Palliative Care

This provides in-person visits, equipment, supplies, and telephone support for patients at home or in community-based care facilities, such as nursing homes and skilled nursing facilities. It is appropriate for patients with low to moderate symptom burden.

Community Home-based HPC through regular visits offers health services to support the care process in the home environment of the patient. It is important within the context of a continuum of care. Studies have shown that home-based HPC can reduce the overall cost of care per cancer patient.^{70,71}

Community Home-based HPC offers feasible and optimal coverage, but it must be supported with active referral networks.

Community-based HPC programs differ from typical home care programs because they are staffed by HPC teams and have stronger expertise in end-of-life care.

In the typical **Home-based HPC**, community health workers, family, friends and volunteers who have been trained to deliver palliative care are the major role players in the care of the patients. They can effectively respond to the majority of patients' needs. Home-based care helps the patient and family maintain privacy and confidentiality and helps to increase community awareness of HPC. Local resources and support networks can be mobilised and training can be provided by community health workers to others in the local area. The integration of family members into the care process means that the patient has easy access to care. Referrals to additional services are made on the assessment of the home care team.

Mobile Outreach Services: This is another variant in which a mobile HPC team visits remote health facilities linked to the parent health facility, to see patients who cannot travel long distances to access care. Care can be delivered by the staff of the HPC outpatient clinic and one of the important features of the outreach service is that it harnesses the strengths of family caregivers. An appropriate referral system should be in place to arrange visits to patients too sick to reach the mobile service, to be seen at home.

Hospice Care

This care facility allows patients to be supported in the community and provides an alternative to dying in the hospital. Patients with incurable life-limiting disease and a life expectancy of 6 months or less would qualify for hospice care. It is more appropriate for community-based care of patients with poor performance status. Recipients are no longer

seeking care at acute care facilities. Hospice care allows patients to be supported in the community and provides an alternative to dying in the hospital.

These five services differ in their team structures, care processes, patient populations, and location of care

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