REPUBLIC OF MALAWI

MINISTRY OF HEALTH

NATIONAL PALLIATIVE CARE POLICY

OCTOBER 2014
This policy was made possible with support from:
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Palliative care improves the quality of life of both adults and children and their families faced with advanced progressive life-threatening illnesses through the prevention, and treatment of pain and other physical, psychosocial and spiritual problems. Palliative care also enhances a patient’s capacity to live optimally and is cost effective when it is an integral part of the essential health care package. The Government of the Republic of Malawi recognizes that palliative care services are required for patients with life-threatening illnesses including; HIV and AIDS, cancer and other non-communicable diseases (NCDs). HIV related Palliative care is particularly important for patients experiencing antiretroviral therapy (ARVs), treatment related side effects; poor adherence and those with HIV related malignancies. The Government also recognizes that palliative care is suitable for orphans and vulnerable children, the elderly and other vulnerable groups.

As such, this Palliative Care (PC) Policy takes forward the national agenda for the health sector as detailed in the Vision 2020 and the Malawi Growth and Development Strategy II. Furthermore, the Constitution of the Republic of Malawi provides for delivery of adequate health care that is commensurate with the health needs of Malawians and as required by international standards. In particular, the Health Sector Strategic Plan 2011-2016 recognizes palliative care as part of the minimum standard of care for people suffering from life-threatening illnesses and should be accessible to all in need of it at all levels of health service delivery.

The Ministry of Health (MoH) is committed to adopt the public health approach for provision of palliative care services by integrating palliative care methods of care in the already existing health care delivery system. In addition, MOH has shown commitment by including disease conditions requiring palliative care (e.g. HIV related conditions, cancer, diabetes, hypertension and other cardiovascular diseases) as part of the essential health package. Furthermore, the Ministry recommends that palliative care is introduced at the time of diagnosis throughout the patient’s disease trajectory with or without disease modifying treatments such as chemotherapy, radiotherapy and surgery, going into end-of-
life care and into bereavement. Such interventions are aimed at relieving pain and distressing symptoms.

Conversely, the Ministry in collaboration with implementing partners has developed this policy to provide a framework for its integration into the health care delivery system of Malawi. This policy is meant to further empower all health professionals, Health Partners, and training institutions to take charge of all initiatives that promote health and reduce suffering in both children and adults. Additionally, the MoH has put in place a mechanism for the coordination and supervision of palliative care services in the country. This policy therefore provides a practical approach to be used by health programs and partners.

The Government of Malawi has the political will to ensure that this Policy is implemented and will be committed to ensure availability of adequate resources for its implementation. In order to achieve this, the Government will work with all key stakeholders in the health sector; including but not limited to the private sector, civil society and others.

I wish to urge all stakeholders to join efforts in operationalizing this national palliative care policy to enable us improve the quality of life of both adults and children including their families faced with life threatening illness by managing pain and controlling distressing symptoms of advanced illness including other psychosocial and spiritual problems.

Dr Jean A. N. Kalilani, M.P
Minister of Health

[Signature]
PREFACE

Malawi, through the Ministry of Health, is committed to ensure adherence to the Palliative Care Conventions and agreements on palliative care. The (2002) Cape Town Declaration positioned Palliative care as a right of every adult and child as such it should be accessible and affordable to all in need, control of pain and symptoms emphasized as a human right necessitating the need for palliative care drugs to be available, training in palliative care for all members of health care teams and providers stipulated as essential and advocated for mandatory availability of palliative care at primary, secondary and tertiary levels. The (2005) Korea Declaration acknowledged that access to trained hospice and palliative care health care professionals, community volunteers and care workers (family caregivers & carers) via existing health care infrastructures as a worldwide problem.

In addition, Malawi is a signatory to the consensus statement adopted at the African Ministers of Health session on Palliative Care at the 2013 African Palliative Care Association /Hospice and Palliative Care Association conference in Johannesburg, South Africa. The delegates at this conference agreed and recommended to support the following six objectives to improve palliative service delivery in their own countries:

1. The development of policy frameworks that strengthen health systems, by the integration of palliative care into hospital and community home-based care health services in order to reduce the suffering of the African people with life-limiting illnesses such as HIV, cancer and other communicable and non-communicable diseases, who are living with pain and other burdensome symptoms.

2. The integration of palliative care services into national health budgets to ensure sustainable services.

3. The use of the already established global and regional frameworks provided by the African Union and WHO, to ensure availability of, and access to, essential medicines and technologies for the treatment of pain and other symptoms being experienced by so many in Africa, including children. This includes the
procurement and distribution of morphine, to ensure greater availability and access of this main opioid for the management of moderate to severe pain.

4. The integration of palliative care into the nursing, medical school and other relevant training curricula and pre-service training programmes such as those for pharmacists, social workers, psychologists and the clergy. In addition, support shall be provided to candidates who desire to take up a career in palliative care. In-service training and capacity building on palliative care for health care providers is also critical.

5. The sharing of palliative care best practices in clinical care, effective models and education across the continent, to ensure peer-to-peer learning across borders. Such practices adopt holistic care approaches that focus on the physical, psychosocial and spiritual aspects of a person’s being, by use of multidisciplinary teams to reduce the suffering of patients with life-limiting illnesses and their families. The provision of palliative care for particularly vulnerable groups such as neonates, children, adolescents, people with disabilities, and the elderly is essential.

6. The development of partnerships across the continent between governments and other players in health, to ensure the sustainability of palliative care responses across the continent as well as promote quality improvement approaches at all levels.

In light of the above, the ministry put in place this policy for palliative care to guide strategy formulation, programming and implementation by all partners in the health sector. This to enable; integration of hospice and palliative care education and training, provision of in service training, support and supervision of professional and non-professional care workers and striving to make hospice and palliative care available to all citizens in the setting of their choice.

In addition, the policy will clarify mandates, roles and responsibilities of various stakeholders at all levels. It is anticipated that the availability of this policy will reinforce
efforts being taken by the Ministry and all key stakeholders in relation to the delivery of palliative care services at all levels.

The development of this policy involved a series of consensus building meetings, consultations and roundtable discussions with key stakeholders. It is the expectation of the Ministry of Health that the policy will provide guidance to key players in its implementation; thereby ensuring a more unified and coordinated effort in the delivery of high quality palliative care services.
ACKNOWLEDGEMENTS

The Ministry of Health would like to specially acknowledge the African Palliative Care Association (APCA), the United States Agency for International Development (USAID) and the Palliative Care Association of Malawi (PACAM) for their contribution towards the development of this policy.

The Ministry would also like to acknowledge the following institutions, individuals and departments for their contribution towards the development of this policy: the Board member - Malawi Health Equity Network, the MOH- Planning Unit, the Directorate of Nursing & Midwifery Services - MOH, the Deputy Director of Nursing Services and Midwifery Services - MOH, the Dean of Nursing & PC Master Trainer - Kamuzu College of Nursing, the Chair- PACAM Board, the Palliative care team leader - Ndimoyo PC Trust, the Deputy Director for Non Communicable Diseases - MOH, the Assistant Director for Non Communicable Diseases - MOH, the PC Nurse - St. Gabriel Hospice, the Director of Monitoring & Evaluation - Nurses & Midwives of Council of Malawi, the Programs coordinator - Lilongwe Catholic Health Commission of Malawi, the Policy specialist - OPC, the Assistant Director, Monitoring & Evaluation - OPC, the national CHBC & Palliative care coordinator-MOH, the Principal Nursing Officer & Palliative care Master trainer - MOH, the National Coordinator - PACAM, the Children’s PC leader- PACAM, the ART/OI Program Manager – MOH, the Principal Nursing Officer - Umodzi Children’s Palliative Care, the Program Manager, - College of Medicine- Bangwe project, the Policy Consultant, University of Malawi, the Hospital Director - Mzuzu Central Hospital, the DMO - Karonga and Nkhatavu Bay District Hospitals, the DHO - Thyolo, Chiradzulu, Mwanza, Dedza and Neno District Hospitals, the Assistant Registrar - Medical Council of Malawi, the Environmental Health Officer - Malawi College of Health Sciences, the College Principal - St. John of God College of Mental Health Sciences, the Palliative care Coordinator - Ekwendeni Mission Hospital, the Board chair for Palliative Care Support Trust and the operations Manager, PACAM.
LIST OF ACRONYMS AND ABBREVIATIONS

AIDS: Acquired Immune Deficiency Syndrome
APCA: African Palliative Care Association
ART: Antiretroviral Therapy
CBO: Community Based Organization
CHBC: Community Home Based care
CHAM: Christian Hospitals Association of Malawi
COM: College of Medicine
DHO: District Health Officer
DMO: District Medical Officer
FBO: Faith Based Organization
GoM: Government of Malawi
HBC: Home Based Care
HIV: Human Immunodeficiency Virus
HSSP: Health Sector Strategic Plan
IEC: Information Education and Communication
ME: Monitoring & Evaluation
MOH: Ministry of Health
NCDs: Non- Communicable Diseases
NGO: Non-Governmental Organization
OI: Opportunistic Infections
OPC: Office of President and Cabinet
PACAM: Palliative Care Association of Malawi
PC: Palliative Care
WHO: World Health Organization
CHAPTER 1: INTRODUCTION & BACK GROUND

1.1 Introduction

The World Health Organization (WHO) defines palliative care 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, psychosocial and spiritual. By this definition, palliative care is applicable early in the course of illness, from the time of diagnosis, in conjunction with other therapies that are intended to prolong life and should not be associated with end-of-life care.

Palliative care is an important public health issue due to population ageing, growing prevalence of non-communicable diseases, particularly cancer, HIV and AIDS in sub-Saharan Africa. Palliative care focuses on improving the symptoms, dignity and quality of life of people with such illnesses and on the care of and support for their families and friends. Management of patients with life threatening and/or terminal illnesses requires a team approach to address their needs and those of their families. Such a team should integrate with all cancer and/or HIV and AIDS treatment services to provide the best possible quality of life for both the patient and their family.

1.2 Historical Background of Palliative Care

Palliative care is an urgent need for patients with HIV and AIDS, cancer, and other non communicable diseases. It dates back to the second half of the fourth century when Fabiola opened a hospice for pilgrims and the sick in Italy. Hospice was used for the dying. In 1967, Dame Cicely Saunders established St Christopher’s Hospice in London which led to the modern hospice movement which is currently being practiced worldwide. In Sub-Saharan Africa, the first Hospice was established in Harare Zimbabwe in 1979 which spread to South Africa in 1980, Nairobi in 1990 and Uganda in 1993. In 2002, Malawi, established the first Palliative care team in the Pediatrics Department at Queen Elizabeth Central Hospital and in 2006 the first hospice Ndimoyo.

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Palliative Care was established in Salima. Palliative care then spread to CHAM, Central and District Hospitals, including NGOs.

1.3 Current palliative care situation

Malawi, like other countries in Sub-Saharan is still faced with the burden of HIV and AIDS, Cancer and other NCDs. There are more than a million people living with HIV and around sixty one thousand deaths per year are attributable to AIDS. It is estimated that about 25 thousand Malawians live with cancer and there are countless others with other diseases who need palliation for which there are no curative treatments available at this time. According to WHO, one percent of the total population is in need of palliative care. Currently, only 4% of the people in need of palliative care are able to access palliative care services.

The majority of patients who need palliative care live in rural and remote areas. In the public sector, oncology services are based at Queen Elizabeth and Kamuzu Central Hospitals. There is no radiotherapy service available in the country and few patients are being managed through referral to other countries such as: Tanzania, South Africa and India. As such, management of patients with cancer from the time of diagnosis requires a palliative care approach with optimal pain and symptom control including psychosocial support.

Mapping of palliative care services has been done and a number of providers identified. There are five palliative centers of excellence and major providers which include: Lighthouse which provides basic palliative care services particularly to HIV infected persons; the Palliative Care Support Trust (PCST) which supports palliative care provision at Queen Elizabeth Central Hospital for both adults and children at Tiyanjane and Umodzi palliative care unit respectively; Ndimoyo Palliative Care hospice which provides palliative care within Salima District; Bangwe palliative care project which provides palliative care in Bangwe catchment are in Blantyre and St Gabriel Family Centered hospice which provides inpatient palliative care and also linking to the
community. In addition, fifty palliative care sites provide palliative care services at all levels of care.

A palliative care curriculum (training manual) for health professionals and Community home based care volunteers was developed, and palliative care is currently integrated into nursing and medical training curriculum. 4250 health professionals have been introduced to palliative care through a short introductory course to palliative care. A number of clinicians and nurses have been trained on pain management including use of morphine, the drug of choice for severe cancer pain. About 30 health professionals have completed postgraduate diploma and degree courses with Makerere University in Kampala, Uganda and Oxford University in United Kingdom in partnership with Nairobi Hospice. Palliative Care Association of Malawi (PACAM), a major collaborative partner of the Ministry was established in 2005 with a mission to advocate and promote palliative care. And in 2010 Cancer Association of Malawi was also established to advocate for needs of cancer patients and their families.

1.4 Rationale for a Palliative Care Policy
The development of this policy has come at an appropriate time when Malawi is increasingly facing enormous burden of HIV and AIDS related diseases including; cancers and other NCDs which were not adequately addressed in other existing health policies.

Palliative care has so far been offered without policy guidance which contributed to a fragmented approach to service delivery. Lack of a policy has brought a number of challenges such as; uncoordinated mobilization and allocation of resources, unstandardized care provision, and inadequate essential medicines and supplies.

The policy therefore aims at ensuring that quality palliative care is provided to all those with life-threatening illnesses in a standardized and coordinated manner. Furthermore, the policy will also ensure the availability and accessibility of quality palliative care services at all levels.
1.5 Linkage with Other Relevant Policies

Malawi has drawn its development agenda in consistence with the Millennium Development Goals, (MDGs) covering 2000-2015 period. The country developed MDGS II with an aim to achieve the MDGs goals. The Ministry has developed the HSSP in order to align its health goals to the overall national development agenda. Therefore, the Palliative care policy falls within the framework of the HSSP. This policy is linked with the following policies, guidelines and strategic plans;

- HIV and AIDS policy,
- National Palliative Care guidelines,
- CHBC policy and guidelines,
- National Infection Prevention and Control policy,
- Malawi Standard Treatment Guidelines and
- Non Communicable Diseases Action Plan

1.6 Key Challenges and barriers

One of the key challenges affecting implementation of palliative care services is lack of integration of palliative care services at all levels of service delivery.

1. **Policy Problem**: Although there are a number of hospitals and other health delivery points that are providing palliative care, the current provision of palliative care services is inadequate and access to the services is not equitable.

2. **Policy Problem**: Despite the growing demand for palliative care there are few cadres (doctors and clinical officers) that are allowed to prescribe opioid medicines. This is due to the prescribed scope of practice. Health workers (nurses, medical assistants) need to be trained on opioid prescription to gain the expected competency to prescribe morphine.

3. **Policy Problem**: Despite the growing demand for palliative care there are few health professionals that have had training in palliative care. This is partly due to the absence of palliative care in the curriculum for most health training institutions. In some cases the few professionals that have been trained do not have access to continued education in palliative care. Community caregivers need to be trained to the expected competences for their level. However, only few community care providers are trained.
4. **Policy problem**: There is shortage of human resource and in most cases the necessary infrastructure for providing palliative care. Provision of quality care is compounded by the unavailability of essential medicines particularly opioids due to lack of funding to procure and distribute to those in need.

5. **Policy problem**: Awareness about palliative care is currently low among both health practitioners and the general public due to the general lack of knowledge about palliative care within society.

6. **Policy problem**: Health care workers sometimes fail to include patients or their families in deciding on diseases management options. Often times patients are given treatment options that would not have been their preferences had they been given the right information and to get involved from the beginning. As a result both parties fail to participate in decisions affecting access to and provision of palliative care.

7. **Policy problem**: There is lack of locally and/or regionally generated evidence for making strategic decisions in palliative care. Some of the reasons for lack of evidence based palliative care practices are inadequate financial resources for research, lack of trained personnel in audit and research within the health sector and poor collaboration among partners. In other cases research findings are not published or disseminated making them unavailable to potential users.
CHAPTER 2: BROAD POLICY DIRECTION

2.1 Vision

Access to quality palliative care for all Malawians in need of it

2.2 Mission Statement

The Ministry of Health will provide access to high quality palliative care through a coordinated care and support that is innovative and responsive to all Malawians with life-threatening illness, their families and care givers

2.3 Guiding Principles

**Multisectral participation:** Palliative care services shall be developed as an integral part of the health care system, based on collaboration between government institutions, non-governmental organizations, and the community. The patient and their family shall be involved in the care in a place that is of the patient’s choice whenever possible.

**Place of care:** Home-based care shall be the cornerstone of palliative care in Malawi and the role of family in the care of chronically ill patients shall be recognized; socially supported, and empowered to cope with the situation. The patient and the family should be the focal points of the palliative care programs. However, palliative care can be provided from other places – hospitals, free standing palliative care units or any other recognized sites.

**Human rights-based approach:** Palliative care is fundamental to health and human dignity and is a basic human right.\(^2\) As such all patients with life-threatening illnesses shall be accorded this right in line with international human rights law.

Palliative care services shall be accessible to all people in need based on the principle of equality and equity (including children), irrespective of their living arrangements or location

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\(^2\) Palliative care is fundamental to health and human dignity and is a basic human right
Comprehensive holistic care: There shall be promotion of the highest quality of life for patient and family at all times. Patients should be able to receive a comprehensive holistic palliative care package that includes access to essential pain and symptom control remedies, including access to opioids, irrespective of place of care. There shall be efforts to educate patients and family to promote their understanding of the underlying disease process and expected future course of the illness.

Umunthu: Palliative Care delivery shall be based on the national values of “umunthu” that emphasize compassion, empathy and humane treatment of all Malawians especially those in need. Ethics and professionalism: All palliative care service providers shall adhere to the principles of medical ethics and delivery of care shall be based on the highest level of professionalism and respect for the rights and confidentiality of patients.

Evidence based care: All decisions on the delivery of palliative care shall be based on empirical evidence through promotion of research on key areas concerning palliative care. There shall be provisions for locally relevant audit and research at various levels for improving the programs and for sharing the experiences.

Coordination and supervision: The Ministry of Health shall be responsible for overseeing the implementation of this policy and will ensure mechanisms for coordination and supervision of palliative care in Malawi.

Capacity building: In consideration of the fact that palliative care is a relatively new philosophy of care in Malawi as well as considering the great need for such a service, the government will encourage health and allied care workers to get at least basic training in palliative care. This training should be for both pre-service and in-serve health care workers to ensure sustainability of the service.

2.4 Overall Policy Goal

The overall goal of the palliative care policy is to improve patients’ quality of life through a system that will ensure the delivery of comprehensive quality services to those in need and scale up of such services.
2.5 Policy Objectives
The following are the specific objectives of this policy:

- To ensure equitable access to holistic, comprehensive high quality palliative care at all levels of health service delivery to patients and their families;
- To enhance capacity among care providers to offer the desired palliative care through an education and training system for health care providers and the general public;
- To facilitate mobilization of resources – human, infrastructural and financial, to ensure initiation and sustainability of palliative care service delivery within the country.
- To ensure that essential palliative care medicines including opioids, are available and accessible to all patients in need irrespective of where they (patients) are.
- To promote and support palliative care for children delivered in a comprehensive matter at a place convenient for the child and his/her family whenever they need such a service.
- To facilitate the delivery of integrated, coordinated and decentralized palliative care services for effective direction and guidance to all palliative care implementers;
- To promote research in palliative care to generate evidence aimed at improving patient care and decision-making.
- To provide guidance for a structured mechanism for monitoring and evaluating palliative care services within the country.

2.6 Policy Application
This policy document will be used as a reference in the development of necessary documents and strategies for an effective implementation of palliative care in Malawi. This policy should be a basis for development of organizational palliative care strategic plans; national palliative care guidelines; M&E tools and protocols; training curricula; as well as communication and advocacy strategies, among others.
CHAPTER 3: POLICY STATEMENTS

This document provides policy statements on key thematic areas which form the basis of practices to guide healthcare providers to achieve the desired outcomes in caring for persons with progressive life-threatening illnesses, as well as assisting their families (caregivers): The thematic areas are as follows:

3.1 Equitable Access to Quality and Comprehensive Palliative Care Services

Access to palliative care is a basic right and as such palliative care should be made available and accessible to all children, adolescents and adults with life-threatening illnesses especially those in need of pain relief and symptom control. Palliative care should be provided by an interdisciplinary team at all levels of health service delivery in Malawi i.e. primary, secondary and tertiary levels to meet patients’ physical, psychosocial and spiritual needs within their cultural context. Such palliative care must be integrated within the existing health care delivery systems, both public and private, as a means of strengthening the health system to ensure scaling up of this important service.

Policy statement:

The Government shall ensure that quality and comprehensive palliative care is available and accessible to all the people of Malawi suffering from progressive life-threatening illnesses.

3.2 Access to pain relieving medicines, particularly Opioids.

It is only registered Doctors and Clinical Officers that are currently allowed to prescribe opioids such as morphine in Malawi. Unfortunately, they are not always available at all levels due to shortage of these cadres. To ensure that pain medications including morphine are accessible to all in need there should be on-going training for health workers providing palliative care about opioids prescription. There should also be a provision that recognizes those trained in opioids prescription and allow them to prescribe as well as on-going training to build capacity of palliative care providers to prescribe and make opioids available and accessible to all in need.
Policy statement:

The Government, in collaboration with professional education regulatory bodies, shall ensure that trained competent palliative care providers prescribe opioids and that all patients who need opioids medicines are accessing it.

3.3 Capacity Building

Health professionals as well as non-health professionals including patient family members are the usual providers of palliative care. To ensure capacity building there should be on-going training for health workers and the general public about palliative care. The human resource department should have a provision that recognizes those trained in palliative care and also ensure on-going training to build capacity.

Policy statement:

The Government, in collaboration with professional education regulatory bodies, shall ensure that palliative care education and training is integrated in all health care training programmes and that there is continuing specialized and competence based education and training for health professionals.

3.4 Resource allocation

Adequacy of resources for the delivery of palliative care is important for an efficient and effective palliative care service. Most important of such resources include human resources, infrastructure and medicines particularly strong painkillers including opioids such as morphine. A palliative care programme cannot exist unless it is based on a rational drug policy that recognizes the importance of opioids in pain and symptom control. Such medicines should be readily available and accessible with well-streamlined distribution mechanisms that would ensure access for medical use while preventing illegal use.

Policy statement:

The Government shall ensure that there are adequate resources to enhance delivery of comprehensive palliative care services in the country to all in need of such a service.

3.5 Information, education and communication (IEC)

All Malawians need to have a better understanding of the concept of palliative care and to know that they have a right to access this care whenever they need it through education and communication of the right information about palliative care.

Policy Statement:

There shall be provisions for raising awareness about palliative care in Malawi through generation of relevant information, education and communication materials.
3.6 Patient and family participation

Participation of patients and/or their families in decisions that relate to the management of their illnesses is very important. A patient feels empowered enough if they are involved in the decision making process about their care.

Policy statement:
* A patient shall be the focus of care together with his/her family when faced with a life-threatening illness and they shall be involved at all times in decisions about their care. They shall be provided with the necessary information and availed with care options.

3.7 Research and results dissemination

The government encourages provisions for evidence-based palliative care practice. Such evidence could be generated locally or from relevant studies generalizable to the situation in Malawi.

Policy statement:
* There shall be provisions for generation of locally relevant evidence through audit and research to improve patients’ care and for sharing the experiences. Collaborative research will be promoted among partner institutions.

3.8 Coordination and supervision

It is critical that provision of palliative care services are well coordinated within the country and properly supervised to ensure standardized service expected for the level of service delivery.

Policy Statement:
* The Government shall ensure that provision of palliative care is coordinated and support supervision provided to ensure standardized provision of care within the country.

3.9 Referral system

Patients with life-threatening illnesses are often referred to either higher lever care centers or back to their communities depending on their needs. A well-established referral network needs to be in place to ensure this.

Policy statement:
* There shall be a streamlined referral system for patients depending on their needs from primary level to higher and back to the community.

3.10 Motivation/Care of the carer

Dealing with patients with life-threatening and/or limiting illnesses can be emotionally draining and providers are bound to get into a complex burnout situation. This applies to both health workers and patient family members who need emotional support and/or otherwise.
Policy Statement:
The Government shall recognize palliative care providers as a special group and provide them with the necessary support that will motivate them carry out this special service.

3.11 Palliative care for pediatric patients
A number of children, adolescents and young adults are suffering with life-threatening diseases associated with suffering. They need to be treated in a special way that recognized their unique needs.

Policy statement:
Palliative care for children, adolescents and young adults shall be recognized as special requiring those with expertise in pediatric palliative care to take leadership in providing such care. The Government shall encourage health professionals to acquire skill in pediatric palliative care to ensure sustainability.
CHAPTER 4: IMPLEMENTATION ARRANGEMENTS

4.1: Institutional arrangement
A coordinated framework for the appropriate delivery of efficient palliative care services is essential. This policy recognizes that Malawi has several established state and non-state institutions that promote the provision of quality palliative care services. Consequently, promoting and strengthening the governance, human resource management, performance management and stakeholder roles of these institutions will be critical. There are various levels of responsibility regarding the implementation of Palliative Care. The roles and responsibilities shall be as follows:

4.1.1 Ministry of Health
The Ministry of Health through the Directorate of Nursing shall:
− provide national leadership and coordination of Palliative Care Services;
− identify, prioritize and support specialized training needs in palliative care;
− monitor and supervise implementation of approved programmes

4.1.2 Zonal offices
The following are the expected responsibilities of the zonal offices:
− monitoring adherence to standards and guidelines at district hospital level;
− supervise, monitor and evaluate the implementation of palliative care services;
− raising awareness about palliative care services in their zones through established media – i.e. IEC materials.

4.1.3 Central Hospitals
Central Hospitals shall:
− provide tertiary palliative care services including having in patient hospital palliative care services;
− ensure collaborative practice for provision of holistic palliative care
− network with community and/or home-based-care groups and other health facilities for referral back to community for continuum of care;
− keep appropriate records and compile quarterly reports.

4.1.4 District Health Offices:
The responsibilities of District Health Offices shall be to:
- ensure adherence to standards and guidelines in the management of palliative care patients;
- allocate financial resources in district implementation plans (DIP) for implementation of palliative care activities at the district and community levels; implement, coordinate, supervise and audit palliative care services at all health facilities within the district;
- participate in the training and certification of service providers;
- designate an officer to monitor the implementation of palliative care services as provided by NGOs, FBOs and CBOs at district level;
- keep appropriate records and compile monthly reports

4.1.5 Health Centers
The responsibilities of health centers shall include:
- developing a palliative care team with involvement of their local communities (including community volunteers) to provide services. The team shall be responsible for identification, management, follow up and referral of patients;
- keeping appropriate records and compile monthly reports which shall be submitted to the district coordinator.

4.1.6 Professional regulatory boards
Professional regulatory boards shall:
- be responsible for regulating and reporting on the importation of narcotics – e.g. morphines and other opioids used in the control of pain and other symptoms;
- review legislation on a regular basis to improve access to opiates
- supervise the safe handling, storage and reporting of opiates at provider sites;
- register and license health care professionals and practitioners including recognizing those specially trained in palliative care;
- monitor implementation of rules and regulations on palliative care.

4.1.7 Central medical stores and facility pharmacies
The roles of medical stores and facility pharmacies shall be to:
- ensure availability and accessibility of all essential palliative care medicines including opioids e.g. morphine;
- keep accurate records of all transactions on opiates.

4.1.8 Civil society
Civil society in collaboration with MOH shall:
- provide supervision to implementing sites;
- provide support for training of trainers;
- identify resources for Continued Professional Development;
- advocate for palliative care services
- advocate for human rights of health professionals, patients and their families
- conduct annual conferences on best practices and update members on emerging issues in Palliative care;
- provide technical support for palliative care services;
- collaborate with national and international palliative care bodies in promoting palliative care in the country;
- monitor adherence to palliative care guidelines and standards;
- Mobilize resources for palliative care.

4.1.9 Health Care Training Institutions
Healthcare training institutions will be responsible for:
- regulating and reviewing existing curricula to ensure there are provisions for training in palliative care;
- training health care professionals in palliative care;
- conducting and dissemination of research findings.

4.1.10 Patients, families and communities
Patients, family members and the community will:
- be involved in establishment and review of palliative care services;
- be actively involved and contribute towards care;
- work in collaboration with health professionals and CBOs/FBOs/NGOs in their catchments area;
- Advocate for better access to palliative care.

4.2: Implementation Plan
The main implementation agency for this policy will be the Ministry of Health. In collaboration with both the public and private sectors, the Ministry will develop a comprehensive implementation plan that will be shared with all the relevant stakeholders. The implementation of the policy will also require significant financial outlays to effect the necessary changes and carryout the necessary programme of activities.
CHAPTER 5: MONITORING AND EVALUATION

5.1 Means of monitoring
The monitoring and evaluation strategy will ensure that palliative care programs are evaluated for progress and identify the strengths and weaknesses of the system. This would be a basis for policy reviews and/or coming up with other strategies. To effectively conduct monitoring and evaluation there will be a need for an advisory panel of experts comprising representatives of government, collaborators, and palliative care providers and community representatives.

5.2 Policy Review
The Ministry of Health through the palliative care program will initiate and facilitate a review of this policy based on identified needs. However, a major review of this policy shall be conducted not later than five years from the date of approval.
GLOSSARY

Comprehensive care: This is the provision of basic care, prevention, treatment, and rehabilitative as well as social support. The key elements of comprehensive care are case finding and management, record keeping, discharge and referral; follow up, family and community mobilization for partnerships with the formal health system, and accessing other forms of community support.

Civil Society: refers to non-governmental organizations, faith-Based Organizations and Community-Based Organizations.

Holistic care: refers to provision of care to the whole person that incorporates the physical, psychological, social and spiritual aspects within the cultural context of the patient and family. Holistic care emphasizes understanding the patient in the context of his environment made of: his family, social group, employment and whole social system that include the extended family and not just the physical aspect.

Essential Health Package (EHP): refers to a set of the most cost- effective, affordable and acceptable interventions for addressing conditions, diseases and associated factors that are responsible for the greater part of the disease burden of a given community. It also proclaims that services will be acceptable and accessible to all citizens.

Palliative Care: is an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness through the prevention and relief of suffering, early identification and impeccable assessment and treatment of pain and other problems such as physical, psychosocial and spiritual problems.
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