

REPUBLIC OF RWANDA



MINISTRY OF HEALTH

Rwanda National Palliative Care Policy

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TABLE OF CONTENTS

Foreword	ii
Acknowledgements.....	iii
Acronyms	iv
Executive Summary	1
Introduction.....	2
Palliative Care: Situation analysis	4
Rationale for the Palliative Care Policy	6
Mission Statement	6
Vision	7
Objectives.....	7
Values and Principles.....	7
Strategic Orientation	8
Characteristics of Care and Services	9
Priority Interventions	9
Guide on Patient Access to Controlled Narcotics.....	12
Policy Implementation	17
Financial Issues.....	17
Monitoring and Evaluation.....	17
Coordinating Mechanisms.....	18
Roles and Responsibilities	18
Conclusion	19
References.....	20

FOREWORD

Over the last decade Rwanda has made significant strides toward improved public health and achievement of the United Nations Millennium Development Goals. By extending the scope of available treatment to include palliative care, other domains such as maternal and child health or the combat against infectious diseases are reinforced.

This Palliative Care Policy represents a significant milestone in Rwandan health care provision. Based on a set of humanist, deontological and professional values, the concept of palliative care guides the attitudes and behavior of health care professionals. Even in the face of chronic and incurable disease, steps can be taken to enhance the quality of life of patients. Indeed, this policy fits well within the existing institutional framework, comprised of important documents such as *Vision 2020*, the *Economic Development and Poverty Reduction Strategy*, the *Community Development Plan* and the *Health Sector Strategic Plan 2009-2012*, which until now has lacked a clear, practical approach to improving the quality of life of Rwandans suffering illness for which we do not yet know a cure.

In the name of equal access to high quality health care, the Ministry of Health is devoted to integrating palliative care into the Rwandan health system. Our steadfast commitment is in light of a recent increase in the incidence of incurable diseases, chief among them HIV/AIDS and cancer. Certainly, all health care stakeholders are called upon to embrace and duly implement this policy, a testament to the innovation and compassion in Rwandan society today.

Dr Richard Sezibera,
Minister of Health

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- The Palliative Care Association of Rwanda, whose support and contributions further facilitated the efforts of the Palliative Care Technical Working Group
- All researchers, physicians, other health professionals, and other stakeholders whose invaluable input helped shape certain chapters of the policy.

We are equally indebted to all those not mentioned here who, directly or indirectly, contributed to the completion of this policy and its supporting documents. Please accept our heartfelt thanks.

Dr Agnes Binagwaho,
Permanent Secretary
Ministry of Health

ACRONYMS

APCA	African Palliative Care Association
CHW	Community Health Worker
HSSP II	Health Sector Strategic Plan 2009-2012
MER	Monitoring, Evaluation and Reporting
MOH	Ministry of Health
NGO	Non-governmental organization
PEPFAR	United States President's Emergency Plan for AIDS Relief
PLHIV	People living with HIV
SWAA	Society of Women against AIDS
UK	United Kingdom
WHO	World Health Organization

EXECUTIVE SUMMARY

The aim of the Rwanda National Palliative Care Policy is to ensure that the policy becomes an essential tool that guarantees good management of patients needing palliative care, guides priority strategic orientations in relation to palliative care, and ensures resource mobilization (human, material and financial) for realization of government programs for the short, medium and long term.

Palliative care provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process and neither hastens or postpones death; integrates the psychological and spiritual aspects of patient care; and offers a support system to help patients live as actively as possible until death as well as a support system to help the family cope during the patient's illness and in their own bereavement. Palliative care requires a team approach to address the needs of patients and their families, including bereavement counseling. It enhances the quality of life, may also positively influence the course of illness, and is applicable early in the course of illness in conjunction with other therapies intended to prolong life such as chemotherapy or radiation therapy. Palliative care also includes those investigations needed to better understand and manage distressing clinical complications.

Strategies outlined in this policy are oriented in leadership, quality of care, information management, client and community management, and health system strengthening. Rwanda's priority interventions will include but are not limited to: integrating standardized services at all levels of the health system, both private and public; ensuring the availability and accessibility of comprehensive palliative care programs and the availability and regular supply of essential palliative care medicines – particularly oral opioids (i.e. morphine); ensuring that patients in need can access essential medicines, including opioids; developing and strengthening legislation that promotes and protects the rights of palliative care beneficiaries and providers; incorporating palliative care into pre-service and in-service training of health workers; mobilizing needed resources to coordinate, implement and monitor palliative care services; and creating awareness and demand for palliative care for all those who need it.

Management, monitoring and evaluation of implemented activities are under the supervision of existing organs and structures in the national health system. Coordination of national policy implementation will be at the central level under the general supervision of the Ministry of Health (MOH). At the peripheral (operational) level, coordination will be ensured by the MOH's decentralized structures, nongovernmental organizations, and other stakeholders.

All people – including children – living in Rwanda with a progressive life-limiting illness, their families, and caregivers will have access to a health system that provides high quality palliative care services that are well coordinated, innovative and responsive to their needs in an affordable and culturally appropriate manner by 2020.

INTRODUCTION

Through *Vision 2020*, Rwanda aims to achieve its objectives through seven strategies and/or pillars which include reducing birth rate, increasing access to education and enhancing health care to the general population. With regard to health care, Rwanda has selected actions and measures that can help enhance the impact of interventions in health and improve health care conditions for the poorest of the poor. For example, antiretroviral drugs have been supplied free of charge since 2003.

The Government of Rwanda recognizes that achieving the Millennium Development Goals cannot be based only on emphasizing infectious diseases only but also non-communicable chronic diseases. Thus the government advocates that palliative care should be adequate and equity be ensured in all aspects of health service delivery including dispensation of palliative care for incurable diseases.

The aim is to ensure that this national policy becomes an essential tool that guarantees good management of patients needing palliative care, guides priority strategic orientations in relation to palliative care, and ensures resource mobilization (human, material and financial) for realization of government programs for the short, medium and long term.

In 2002, The World Health Organization (WHO) defined palliative care as “an approach that improves the **quality of life** of patients and their families facing the problems associated with life-threatening illness, through the **prevention** and **relief of suffering** by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

The WHO (2002b) definition of palliative care goes further to say that palliative care:

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Neither hastens or postpones death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patient’s illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counseling;
- Will enhance quality of life, and may also positively influence the course of illness;
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

The WHO (1998) also provides a special definition of palliative care for children and their families:

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological and social distress.
- Effective palliative care requires a broad multi-disciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.

Palliative care can be provided in tertiary care facilities, in community health centers and even in clients' homes. Stjernswärd, Foley and Ferris (2007) outline five pillars as necessary for a palliative care public health strategy to be integrated into national health systems: appropriate policies; adequate drug availability (including opioids); education of health care workers and of the general public; implementation of palliative care services at all levels throughout the country; and provision of psychological and spiritual support or other community and home-based care supports.

In 2004, the MOH sent a multidisciplinary team to Uganda to gain experience from the development of the Ugandan palliative care delivery system. In October 2005, the first training in palliative care was organized by The Society of Women against AIDS (SWAA) and Help the Hospices UK. This training took place at King Faysal Hospital and 26 health professionals were trained. Further training was later conducted in 2005/2006 by the African Palliative Care Association (APCA), where 25 health professional were trained. Later in 2008, a team from the IntraHealth International HIV/AIDS Clinical Services Program began training in palliative care in four district hospitals—Kibagabaga, Nyagatare, Rutongo and Byumba Hospitals—as well as their respective health centers.

Despite this training, palliative care in Rwanda is still in its infancy, with some autonomous community-based organizations or nongovernmental organization (NGOs) providing home care to vulnerable people, especially people living with HIV/AIDS (PLHIV). Most of these efforts in palliative care through home care were supported by Partners in Health which has trained community health workers (CHW) known as coaches. These coaches distribute antiretroviral medication and support patients to increase their adherence to medication.¹ However, Rwanda lacks the capacity to deliver palliative care at all levels and has also needed a policy to underpin palliative care service development.

¹ Rwinkwavu and Kirehe hospitals train staff from the community who are known as coaches. Their role is to distribute antiretrovirals in the morning and evening to PLHIV. Each coach receives from Partners in Health RWF 8,000 per month per household, to a maximum of RWF 23,000.

PALLIATIVE CARE: SITUATION ANALYSIS

A survey was conducted from May to June 2009 in 15 district hospitals, 14 health centers, a hospice and households of those traumatized by the genocide within the four provinces of the country and Kigali City to identify the current situation as far as palliative care was concerned. 236 patients and 31 caregivers were interviewed. Survey findings included the following:

- Service delivery did not optimally respond to the needs of beneficiaries of palliative care or their families;
- One salient weakness in the palliative care delivery system was the poor referral and guidance mechanisms meant to enable access to services at the right time. This creates gaps in the continuum of healthcare and services when referrals are not effective.

In a nutshell, current scarcity of qualified, skilled and experienced human resources to deliver palliative care in homes and/or health institutions as well as lack of tools and laws that enable health care workers to prescribe opioids and manage patients at home means that there is need for strong advocacy for quality services. This advocacy will also include training programs, development of tools for palliative care service delivery, and the promulgation of laws governing palliative care delivery especially the prescription of opioids.

Strengths:

- Availability of trained staff in palliative care; 26% of the surveyed institutions had at least one trained staff;
- 6.4% of the country's health structures supported palliative care development through establishing and/or strengthening clinics treating chronic diseases;
- Patients who suffered incurable diseases, particularly were followed up through health centers;
- There was a structured organization of health centers to facilitate monitoring of people needing psychosocial support within communities, at home by nurses and social workers as well as those trained in community health;
- A multidisciplinary management of patients at the basic level of health care existed up to the level of referral hospitals, allowing continuity of care;
- There was generally a good attitude towards patients with terminal stages as shown by 81% of caregivers.

Weaknesses:

- Lack of a policy and laws for the development and management of palliative care services;
- Lack of a palliative care training plan for staff in all health structures;
- Lack of skills in providing palliative care at all levels of the health system particularly at the level of health centers that do not have any physician;

- Poor monitoring of progression of chronic diseases among patients with incurable diseases especially those that are life threatening (cancer, heart failure, kidney failure, liver cirrhosis, and paraplegia);
- Lack of a well defined and well coordinated referral system between hospitals, health centers and home;
- Prescriptions of strong opioids limited to district and referral hospitals only, and restricted use of oral opioids in homes. In the survey, 17 institutions (54.8% of health centers, hospice and home) were not authorized to prescribe any strong opioids, even for terminally ill patients with cancer who were at home or who had been transferred by referral hospitals to health centers;
- Lack of oncologists and facilities such as radiotherapy wards;
- Financial inaccessibility to treatments such as dialysis for kidney failure cases.

Opportunities:

- Political will to improve public health allowing the allocation of sufficient resources to this sector for better management of health among the poor;
- The government ratified conventions and protocols related to human rights, women's rights and children's rights which should be respected. These can be used as tools to advocate for equity in access to palliative care;
- Strong partnership among international organizations, local NGOs and community-based organizations that offer services and support both financially and technically;
- Existence of community health workers, at least five per village (*umudugudu*) and other volunteers in services at the community level. Capacity building of the workforce is an asset in successful management of palliative care at home and in the community;
- Performance-based funding (contractual and top-up approach) leads to enhancing quality of health services.

Threats:

- Instability of development partners in the health system;
- Extreme poverty of the population;
- High illiteracy at the community level.

Challenges:

- Lack of policy and laws to govern the management and development of palliative care;
- No strategy for training staff in all health structures in palliative care;
- Poor skills in delivery of palliative care services at all levels of the health system particularly at the level of health centers which do not have any physician;
- Inadequate monitoring of chronic pathologies, amongst them incurable diseases threatening life (cancer, heart failure, kidney failure, liver cirrhosis, and paraplegia);
- Poor referral networks between district and referral hospitals and health centers;

- Limited opioid prescription capacity at the district level and restriction to issue oral opioids in their homes for those referred to health centers. In fact, 17 institutions which represent 54.8% (health center, hospice and home) were not authorized to prescribe any strong opioids, even for terminally ill cases of cancer who were at home or who were transferred by referral hospitals to health centers;
- Lack of oncologists and treatment options such as radiotherapy for the treatment of cancer.

RATIONALE FOR THE PALLIATIVE CARE POLICY

Improving the quality of care as outlined in the Health Sector Strategic Plan 2009-2012 (HSSP II)² is imperative for greater satisfaction of users. However, healing may not be possible in spite of the caregivers' willingness to mobilize all available resources. It is at this particular phase of life that palliative care which is a component of the health system for patients with chronic and incurable diseases has become indispensable.

However, the health system in Rwanda is not yet focused on non-communicable incurable diseases. This requires restructuring with special attention to palliative care, equity and accessibility to quality general health care. The high cost and sophistication of managing those incurable diseases which directly threaten life is further complicated by limited resources such as medical and non-medical qualified personnel, and poverty (the majority of the population lives below the poverty line). The rising incidence in incurable pathologies dominated by HIV (45% of the surveyed population) and cancer (28% of the surveyed population) constitutes a rationale for studies that aim to find appropriate solutions.³

The MOH has taken the initiative to develop the Rwanda National Palliative Care Policy in order to respond to the above challenges. This policy was developed via consultation and in agreement with other policy makers, existing databases and various reports, as well as from research and guiding documents produced and identified in Rwanda as well as in other countries.

MISSION STATEMENT

All Rwandan people living with a progressive life-limiting illness, including children and people living with disabilities, their families and caregivers will have access to a health system which provides high quality palliative care services that are well coordinated, innovative, and responsive to their needs.

² In *Vision 2020*, Rwanda proposes to improve health of the population, and health policies focusing on improving access, quality and cost of health care.

³ Survey report *Etat des lieux des soins palliatifs au Rwanda*, written in August 2009 by Dr. Nyamwasa Daniel, shows that over six incurable diseases identified threaten directly life, the most recurrent/ frequent is HIV and cancer and they respectively represent 45 % and 28% of the surveyed population.

VISION

All people with life-limiting illnesses in Rwanda will have access to quality palliative care services delivered in an affordable and culturally appropriate manner by 2020.

OBJECTIVES

Main Objective: To ensure that palliative care services are available to all people, including children and people living with disabilities, who need them in Rwanda.

Specific objectives:

- To ensure accessible (available and affordable) palliative care programs throughout Rwanda that are adequately resourced.
- To integrate palliative care services into the whole spectrum of the national health care system in Rwanda.
- To ensure the availability of essential palliative care medicines, particularly oral opioids (e.g. morphine) and other related medicines at all levels of the health system.
- To develop and strengthen legislation that promotes the welfare and freedom of choice of palliative care beneficiaries and protects palliative care service providers.
- To integrate palliative care training into pre-service and in-service training programs for all cadres of health workers.
- To establish a framework for palliative care service provision in Rwanda supervised and coordinated by the MOH.
- To develop indicators and strengthen structured mechanisms for monitoring and evaluating palliative care programs.

VALUES AND PRINCIPLES

In carrying out its mission in terms of palliative care in Rwanda, the MOH will always rely on the values of solidarity and equity, ethics and cultural identity. It is also guided by principles of acceptability and quality of care, effectiveness and efficiency, coordination, community participation, decentralization, and integration of services and care.

Other underlying principles include:

- Developing palliative care services based on a public health approach that includes policy, implementation, education and drug availability;
- Ensuring equity in access to care and financing of health services for the population as a whole, particularly in palliative care;
- Providing quality palliative care that is safe, appropriate, effective, accessible and adequately resourced;

- Planning, organizing and delivering services based on the needs and choices of beneficiaries;
- Keeping beneficiaries in their usual life context as they wish (e.g. being cared for at home);
- Putting in place multidisciplinary care units and teams that abide by these principles;
- Continuing education of palliative care providers.

The Rwanda National Palliative Care Policy is based on principles in the medical code of conduct the goal of which is to strengthen the humanization of care. These principles for success include:

- Respect for dignity and integrity of the individual;
- Respect for the freedom of the individual to choose;
- Respect for privacy and confidentiality of the person;
- Respect for privacy, dignity and confidentiality of children;
- Skills of the physician and medical team.

Ethical issues are very critical in palliative care, as the practice of palliative care raises questions in relation to control that the beneficiary and her/his relatives or caregivers wish to exert on the disease and death. Major issues include refusal and/or termination of treatment, use of intensive medication, continued sedation and euthanasia.

The right to refusal and/or termination of treatment provides the beneficiary with rights to refuse any treatment, including those whose objective is to prolong life. Such rights should be embraced by the country's legal system.

The law should ensure that each person whose status requires it shall have a right to access palliative care and support provided either in an institution or at home by a multidisciplinary medical, nursing and home-based care team. The obligations to the patients of public or private health institutions and medical-social institutions in terms of pain and other symptoms management should be outlined clearly by the palliative care policy.

STRATEGIC ORIENTATION

Leadership: By focusing on diagnosis, active listening and deep inspiration, leaders are invited to focus on important elements calling upon development partners to line up behind the government's policy and mobilize funds accordingly.

Quality of care: This is a motto for all health services in Rwanda. Quality services are key elements for the Rwandan health system to ensure sustainability and motivate community use of services in general and for palliative care in particular.

Information management: A key element of palliative care services is the use and rational exploitation of information that helps evidence-based decision making. This should be promoted by both users and development partners.

Clients and community management: Clients, active members of society, have rights and responsibilities in health service delivery. The client charter, good governance and accountability constitute key elements for successful and sustainable socioeconomic development.

Health system strengthening: Investing in health for sustainable development requires important contributions by local human resources and external technical expertise. Key elements of a good multisectoral approach include the availability and pre-positioning of medicines and consumables; reliable finance mechanisms including health insurance of all kinds; and resource-generating projects.

CHARACTERISTICS OF CARE AND SERVICES

In order to respect the abovementioned values and principles, the MOH has defined the characteristics of care and services in palliative care. These characteristics of care include continuity, integration, globalism and relevance. Services are further characterized by the process of decentralization, permanence, versatility and efficiency.

PRIORITY INTERVENTIONS

Deliver services at all levels of the health care system in Rwanda, both private and public

In an effort to reconcile quality care and financial income, private health care providers will be encouraged and supported to provide palliative care to those who access their services. To ensure equity of care throughout the country, the MOH will mobilize caregivers from the private sector and negotiate rates for service delivery but also allow the use of community-based health insurance schemes (*mutuelle de la santé*) in this sector. Agreements or memoranda of understanding will be negotiated and signed between the MOH and the private sector to increase availability and accessibility of services to those populations that have been hitherto excluded. This will also benefit the private sector as its clientele will increase. Caregivers in the private sector will be encouraged to integrate palliative care services into the routine care they provide to their clients. Capacity will be built among health professionals to enable teamwork, cooperation, communication and integration of care among service providers of different disciplines at the different levels of health care.

Ensure the availability and accessibility of comprehensive palliative care programs throughout the country

This intervention targets the creation and dissemination of a culture of palliative care both among health professionals and the public, and aims to enhance preparedness for the delivery of palliative care services, ensuring that palliative care is provided at the different health levels and in different settings, and that issues of equity, quality and accessibility of services are addressed. Creating multidisciplinary teams of physicians, nurses and social assistants to provide 24-hour medical services, including home visits and/or telephone communication whenever possible, is key. Continued nursing care should be available as needed or requested and psychosocial support services by health centers should be available whenever necessary to

support the beneficiaries and their families in the community. Spiritual support services, physiotherapy and nutritional support, though they do not require sophisticated means, are also indispensable and should be provided as part of the palliative care service package either at the health facility or in the home. Community pharmacies should be established wherever feasible to enhance drug availability and accessibility.

Ensure that palliative care is integrated into the whole spectrum of health service delivery

Palliative care will be integrated into the health care delivery system, including in the national treatment guidelines, and appropriate training will be provided at all levels of the health care delivery system

Standardize the delivery of palliative care services for people with life-limiting illnesses, including children, following a primary and public health care approach

This will be possible by developing a framework for addressing children's palliative care needs.

Ensure the availability and regular supply of essential palliative care medicines, particularly oral opioids (e.g. morphine) and other related medicines at all levels of the health system

The implementation of this intervention will be made possible by: ensuring the availability of palliative care medicines, including opioids, at all levels of the health care system; ensuring the availability of trained palliative care providers at all levels of the health care system who can prescribe palliative care medicines including opioids; and increasing the number and type of cadres at all levels who are able to prescribe such palliative care medicines.

Ensure that patients in need can access essential medicines (including opioids) as and when they need them at their preferred places of care – including in the home

Activities as part of this intervention will include: the development of national guidelines for pain assessment and management; identification of pain assessment scales that are appropriate and can be used in Rwanda; adherence to the WHO's Pain Management Ladder; review of the regulations for procurement, storage, transportation and use of opioids; development of country-specific guidelines for use of opioids; making oral morphine available to all levels of care; and reviewing the process of prescribing regulations around the use of opioids.

Establish and promote national standards for palliative care service provision at all levels of the health system

This will be made possible by developing a framework to ensure quality palliative care throughout Rwanda by developing palliative care standards for Rwanda and by putting in place a quality assessment system to ensure that each provider fulfills her/his obligations and that services meet quality standards and regulations. This system should include assessment of the satisfaction of beneficiaries and their relatives with services received.

Develop and strengthen legislation that promotes and protects the rights of palliative care beneficiaries and those of palliative care service providers

Criteria for accessing palliative care services should be clearly set and standardized for the different levels and sites of care. Equity in accessing care implies that financial contributions from beneficiaries to palliative care shall be standardized countrywide according to levels of health care and that no one shall be refused palliative care on financial grounds.

Ensure capacity development of all those involved in the provision of palliative care for effective and efficient service delivery e.g. health care workers, community health workers and community volunteers

The government will integrate palliative care training into the training of all health care workers both medical and non-medical at the various levels of the health care system and will establish a framework for the coordination of palliative care services in Rwanda. The MOH will supervise, coordinate and regulate the provision of palliative care services and ensure continued education in palliative care.

Ensure that palliative care is included in pre-service and in-service training of health workers, to prepare them for effective and efficient palliative care service delivery

The government will integrate palliative care training into pre-service and in-service training programs for all cadres of health workers, and will ensure that health professionals have basic training in palliative care. Key strategies to succeed include the integration of palliative care at all levels of professional and non-professional health worker training in Rwanda, to equip them to deliver palliative care services as needed, and creation of opportunities for in-service training and continuing medical education.

Establish and promote quality standards in palliative care training.

The government will provide palliative care providers with specific operational guidelines and benchmarks to facilitate the provision of quality palliative care. The operational guidelines and benchmarks will form the Standards and Guidelines for the Provision of Palliative Care for Incurable Diseases. The Standards and Guidelines will be applicable to all settings of palliative care delivery, i.e. home based care, inpatient services, outpatient programs, day care programs, hospital settings and all those innovative models that are currently used in Rwanda. The Standards and Guidelines will be the tool for quality improvement and outcome measurement for service providers, administrators, and relevant stakeholders, including donors, for palliative care services.

Mobilize adequate resources to ensure effective coordination, implementation, monitoring and sustainability of palliative care programs

Key strategies to implement this intervention include: developing dedicated budget lines in the national health budget for palliative care provision; establishing a framework for the coordination of palliative care services in Rwanda; developing a national monitoring and evaluation program for palliative care; and developing a coordination and regulatory mechanism palliative care service provision.

Create awareness and demand for palliative care among all those who need it

It will be necessary to implement awareness campaigns on palliative care and support services and establish a telephone line the purpose of which will be to respond to the need for information, advice and support in palliative care. The media—both public and private—will be used during campaigns to sensitize communities about palliative care, explaining what it is and where such services can be accessed throughout the country, and to advertise and organize debates during community activities to pass information on to the public in a common language.

GUIDE ON PATIENT ACCESS TO CONTROLLED NARCOTICS

The Single Convention on Narcotic Drugs (Schedule I) defines substances that have a high abuse liability or are convertible into drugs that are liable to abuse. They include cannabis resin, narcotics, stronger opiate analgesics (morphine, oxycodone), members of the ecgonine-cocaine drug family, and a large number of synthetic drugs (fentanyl and its analogues, methadone).

The Single Convention of Narcotic Drugs (Schedule II) defines substances that are less liable to abuse than those in Schedule I such as codeine and its derivatives.

This guide will explain the procedures for patient access to and the safe management of Schedule I and II drugs that are necessary for the treatment and relief of moderate to severe pain. It provides procedures for acquisition.

International regulations

This guide is underpinned by international regulations and conventions to which Rwanda is party. The 1961 Single Convention on Narcotic Drugs, amended by a 1972 Protocol, regulates opioid use. The convention recognizes that medical use of narcotic drugs continues to be indispensable for the relief of pain and suffering and that it is the government's obligation to ensure adequate provision and availability of narcotic drugs for such purposes.

The central Principle of Balance represents a dual imperative for governments to establish a system of control to prevent abuse, trafficking and diversion of narcotic drugs while at the same time ensuring medical availability.

Transportation regulations

Article 30(1) of the convention requires that all enterprises and persons in the distribution system should be appropriately licensed or authorized. With regard to transporting medicines, the following actions are recommended to meet the requirements of the convention:

- The drug regulatory authority issues the relevant drivers/person with a special license to allow the carriage of narcotic medicines.
- The wholesaler, importer or manufacturer checks the transporter identification.
- The transporter checks the medicines and records his/her name, signature and the date on the original and copy the invoice. A copy of the signed invoice should be kept by the wholesaler, importer or manufacturer, and the original (signed) invoice is taken by the transporter.
- The transporter carrying these medicines is not allowed to carry any passengers other than staff approved by the company.
- The vehicle needs to be kept locked at all times except when loading and unloading, and the key held by the same transporter.
- It is the responsibility of the transporter to report to the nearest police station (within 24 hours) any loss of medicines from the vehicle.
- On arrival where the drugs need to be delivered, the transporter hands over the medicines to the person in charge, who checks the medicines and invoice in presence of the transporter. The invoice is kept in the pharmacy in a secure place for a required period as per government regulations.

Who can prescribe narcotics?

Article 30(B) of the convention does not specify who may or may not prescribe controlled medicines, but says that "a medical prescription" is required for the supply and dispensation of drugs to individuals. Those permitted to prescribe narcotics/opioids are defined in national laws or regulations governing medicines in each respective country.

In Rwanda only a registered physician will prescribe narcotics/opioids for palliative care. The health center can follow up and make requisitions for its patients.

Prescription details

The convention does not specify any limits on the amount or duration of prescriptions. This guide therefore recommends that prescriptions be written in amounts and for a period long enough to allow ample time for patients to travel long distances, or long enough to last the patient until the next appointment.

The following details are recommended to be included in prescriptions:

- Name and address of patient

- Date of issue
- Medicine name, dosage strength and form
- Directions for use
- Total quantity of medicine to be dispensed written in both figures and words
- Duration
- Prescriber's name and business address
- Prescriber's signature

Who is allowed to dispense?

The medicine should be dispensed by a registered pharmacist at district level. It should be the responsibility of the chief pharmacist to ensure a continuous supply of controlled medicines so that shortages that could lead to interruptions of pain relief for patients do not occur.

The district should send the medicine to the health center nearest the patient with all records and the patient will have one week's provision. At this level the provider should carefully check the details of the prescription as specified above.

Any dispensing should be checked by another member of pharmacy staff, or other trained and licensed staff.

The patient, relative or staff member who receives the medicine should sign in the register/record book. Prescriptions should be kept in the pharmacy for at least two years from the date of dispensing for future inspection.

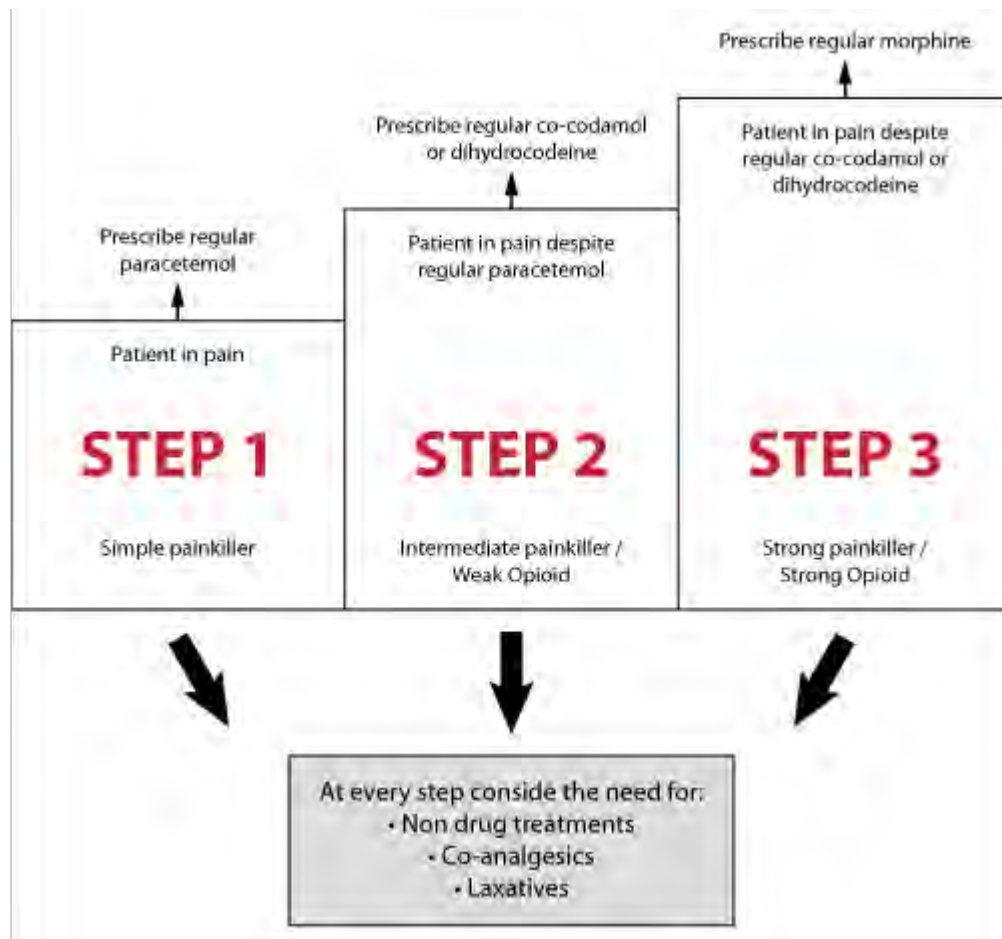
At home

For home-based care any dispensing should be checked by another member of the home care staff, such as a trained CHW. All medicine should be kept in a secure locked cupboard at all times. The patient should be visited in the first week by a team of a nurse and a CHW and afterwards the CHW will continue regular visits as needed. The nurse should send the medicine home for very ill patients.

Health workers must ask to see any medicines (including traditional medicines) that the patient is currently taking.

Any medicine that is no longer required should be stopped and recorded, and the reason specified. The patient and care provider should be given a chart (medicine chart) detailing the medicine and how it should be taken. The current date and date of next visit should be filled in.

WHO 3-step Ladder



Gold standard

In 1968, McCaffery defined pain as “whatever the experiencing person says it is, existing whenever he says it does.”

According to the list of essential medicines of Rwanda, all three steps will be used at the health center level with district hospital supervision. The center must have a registered nurse trained in narcotics management. Therefore the reference system should be strong to be sure that all information is passed to the right person at the correct time.

A system must be set up to alert health service providers if a client misses appointments at the clinic. There must be a plan of action to address missed appointments, e.g. a home visit or an inquiry sent to CHWs asking them to visit the home of the person who did not turn up for the appointment.

Good documentation and record keeping are necessary. Required documentation includes the following:

Central level:

- Importation documents
- Monthly inventory reports
- Monthly distribution report showing quantities dispatched, date of dispatch and who received the product

District level:

- Requisition documents
- Monthly inventory reports
- Monthly distribution report showing quantities dispatched, date of dispatch and who received the product

Facility level:

- Requisition documents
- Monthly inventory reports
- Monthly distribution report showing quantities dispatched, date of dispatch and who received the product

Community level:

- Prescription from recognized physician
- Weekly inventory reports
- Weekly distribution report showing quantities dispatched, date of dispatch and who received the product

On each of the abovementioned documents, signature of the person delivering and the one receiving the product are mandatory (even at community level: patient or caregiver).

Tools that support these procedures must be developed and harmonized at each level by the MOH, and filled every day after each transaction.

Regulatory institutions have to follow up and have to make sure that tools are completed correctly and reports regularly sent.

ANY UNJUSTIFIED QUANTITY IS SUBJECT TO PENAL SANCTIONS.

POLICY IMPLEMENTATION

Palliative Care Implementation Strategy

Palliative care implementation is wide and complex, requiring considerable resources both human and financial. These resources are scarce. For implementation to succeed, four components need to be in place:

- Assess the current situation (where are we today?): This will assist the planners to identify strategic, structural, cultural and technical aspects that will have to be taken into consideration during implementation of palliative care services.
- Develop a training and skills-building plan to facilitate implementation.
- Develop a communication plan that will link all players in palliative care service delivery to each other and to patients and their families.
- Develop a technology plan to put in place tools necessary in the provision of palliative care e.g. visual catalogue scales, reference materials to support health workers during service delivery and so on.

Priority strategies

Priority strategies for the Rwanda National Palliative Care Policy will include:

- Developing and strengthening palliative care at all levels in the country health system, including at home and in the community;
- Sensitizing the public to palliative care, its necessity, availability and accessibility;
- Improving access to quality palliative care;
- Developing human and financial resources, as well as research in palliative care.

FINANCIAL ISSUES

The source of funds is the MOH; it should involve the Ministry of Finance and Economic Planning and closely collaborate with donors. The budget shall be allocated to training caregivers, to research and to purchasing drugs and materials.

MONITORING AND EVALUATION

There needs to be a clear monitoring, evaluation and reporting (MER) plan for the successful implementation of the Rwanda National Palliative Care Policy as per the objectives of the policy, with clear measurable indicators linked to the implementation plan. The MER plans will include a global review of the policy implementation process and identify components that need adjustment in the course of policy implementation.

Lessons learned and the outcome of evaluation can serve to improve ongoing planning and implementation of the various activities. It should be very clear as to who is responsible for MER functions at the various levels of palliative care service delivery. The evaluation component will gauge the following:

- Relevance of the palliative care policy and whether the activities and achieved results correspond to the initial objectives;
- The level of achievement of targeted objectives, and where appropriate, ways of achieving those objectives more efficiently;
- Performance of health service providers and if the services provided meet set standards.

COORDINATING MECHANISMS

Management and MER of implemented activities will be implemented by existing organs and structures in the national health system, including the palliative care technical working group and development partners, under the supervision and coordination of the MOH. At the peripheral (operational) level, coordination will be ensured by the MOH's decentralized structures, NGOs and stakeholders.

Evaluation should begin no later than six months after the official date of validation and launch of the Rwanda National Palliative Care Policy.

ROLES AND RESPONSIBILITIES

Community level: Identify palliative care stakeholders; provide palliative care services and supervise morphine prescription and use at home level; provide pain management services; monitor, evaluate and report palliative care activities to the next level (health center).

Health center level: Set up a structure of governance that is the palliative care multidisciplinary team and strengthen its capacity; train health staff in palliative care at community level; quantify and procure morphine; supervise palliative care activities at community level; distribute MER tools including Morphine Manual and guidelines on distribution and use of morphine at community level; provide pain management services; monitor, evaluate and report palliative care activities to the next level (district hospital).

District hospital level: Set up a structure of governance that is the palliative care multidisciplinary team and strengthen its capacity; train health staff in palliative care at health center level; quantify and procure morphine; supervise palliative care activities at health center level; distribute MER tools including Morphine Manual and guidelines on distribution and use of morphine at health center level; provide pain management services; evaluate and report palliative care activities to the central level (MOH).

Medical schools (NUR and nursing schools): Develop training curricula and teaching materials including updated guidelines on palliative care and on morphine management; organize palliative care e-learning system; organize in-service training workshops in palliative care; document best practices in palliative care including morphine management.

Private sector: Set up a structure of governance that is the palliative care multidisciplinary team and strengthen its capacity; train health staff in palliative care at private health clinic level; quantify and procure morphine; supervise palliative care activities at private health clinic level; distribute MER tools including Morphine Manual and guidelines on distribution and use of morphine at private health clinic level; provide pain management services; evaluate and report palliative care activities to the central level (MOH).

Reference hospitals: Set up a structure of governance that is the palliative care multidisciplinary team and strengthen its capacity; train health staff in palliative care at district hospital level; quantify and procure morphine; supervise palliative care activities at district hospital level; prepare MER tools including Morphine Manual and guidelines on distribution and use of morphine; participate in the development of training curricula and teaching materials including updated guidelines on palliative care and on morphine management; organize a palliative care e-learning system; organize in-service training workshops in palliative care; document best practices in palliative care including morphine management; provide pain management services; evaluate and report palliative care activities to the central level (MOH).

Ministry of Health: The MOH sets up policies, strategic frameworks, guidelines, standards and regulations related to palliative care. It supervises palliative care services at referral and district hospitals. It identifies sources of funding and ensures equitable distribution of those funds. The MOH is responsible for other resource management including qualified human resources. It is also responsible for regulations in terms of morphine abuse by establishing morphine abuse regulations, policy and implementation mechanisms.

CONCLUSION

The Rwanda National Palliative Care Policy promotes a holistic approach to patient care and outlines proposals for integrating palliative care into the Rwandan health care system. The policy also aims to put a human face to the end-of-life period through humane and compassionate care for the patient and her/his family, ensuring that such care is available to all those who need them, including children.

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