Palliative Care in Southern Africa

Review of current policies and opportunities for scaling up care
Acknowledgements

The African Palliative Care Association (APCA) extends sincere gratitude to the national governments of Angola, Botswana, Democratic Republic of Congo (DRC), Lesotho, Malawi, Mozambique, Namibia, Swaziland, Zambia and Zimbabwe for allowing APCA to undertake a review of national policies and national implementation frameworks in order to achieve the goals of this project. In addition, APCA thanks the in-country partners who provided local support and logistics for the project. We also owe a debt of gratitude to our consultant, Jenny Hunt, whose tireless efforts in supporting the rapid appraisals ensured that the project was a success.

Lastly, APCA thanks the Open Society Foundations (OSF), New York and the Open Society Initiative for Southern Africa (OSISA) for funding the project.
Foreword

With the huge burden of cancer, HIV, and other life-limiting illnesses across Africa, a clear public health argument exists for the availability of pain- and symptom-relieving drugs to enhance the quality of life of millions of people, to maximise clinical benefit from available treatments and to ensure freedom from unnecessary suffering. Despite this, many barriers exist that prevent access to palliative care (and particularly access to effective pain medication for patients in need) on the continent.

In 1995, the International Narcotics Control Board surveyed government drug control authorities. It identified multiple barriers, similar to the barriers being identified today, including:

- excessively strict national laws and regulations;
- fear of addiction, tolerance, and side effects;
- poorly developed health care systems and supply; and,
- lack of knowledge on the part of health care professionals, the public, and policy-makers.

While these barriers pose a great challenge to accessing pain medication (amongst other things), the absence of national policies and lack of government understanding about the importance of pain medication exacerbates them. The Open Society Foundations (OSF), based in New York, and the Open Society Initiative for Southern Africa (OSISA) funded the African Palliative Care Association (APCA) to undertake a review of national policies and national implementation documents across ten African countries, to assess the extent to which palliative care pain medication and associated gender issues are addressed in these policies. In addition, the review looked at gaps and opportunities to increase access to palliative care for all those who need it.

This report provides useful insights into how the issues reviewed have been addressed across the target countries, and offers recommendations and suggestions on how governments can address these challenges at the policy level. While this report does not provide a review of all the national policies, it examines a cross section of policies that could be relevant in palliative care development, and also provides a review tool which governments, or others interested in undertaking a similar review, can use to assess progress in their countries.

APCA, OSF, and OSISA strongly recommend the inclusion of palliative care in national policies so as to ensure:

- identification and setting of priorities for palliative care development in each country;
- identification and allocation of resources needed to support these priorities and provide a basis for resource mobilisation;
- collaboration between relevant stakeholders, including governments, civil society, institutions of higher learning and private agencies;
- a framework for standards that can underpin access to effective palliative care; and,
- appropriate planning.

We hope that this report will encourage governments, national stakeholders and palliative care providers to work together to establish policies that will meet the palliative care needs of patients with life-threatening illnesses, reducing unnecessary pain and suffering across Africa.

Faith Mwangi-Powell, Mary Callaway and Vicci Tallis
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Abbreviations and acronyms

AIDS Acquired Immune Deficiency Syndrome
APCA African Palliative Care Association
DRC Democratic Republic of Congo
FAO Food and Agriculture Organization (UN)
FGD Focus Discussion Group
FHI Family Health International
HBC Home-Based Care
HIV Human Immunodeficiency Virus
IPCI International Palliative Care Initiative
KII Key Informant Interview
MSM Men Having Sex with Men
NGO Non-Governmental Organization
OSF Open Society Foundations
OSIEA Open Society Initiative for East Africa
OSISA Open Society Initiative for Southern Africa
PLWHA People Living with HIV or AIDS
PPSG Pain and Policy Study Group
WHO World Health Organization
Executive summary

In many African countries, palliative care is not yet integrated into national policies so public health access is not available to the majority of those who require palliative care. The African Palliative Care Association (APCA) embarked on a project that aimed to review national legislation and policy documents and implementation strategies across ten African countries to identify and assess ways to support palliative care scale-up at the national level. The countries included in the review were Angola, Botswana, the Democratic Republic of Congo (DRC), Lesotho, Malawi, Mozambique, Namibia, Swaziland, Zambia and Zimbabwe.

The review was undertaken using a review tool that was developed using existing information on policy, gender issues and palliative care. However, because there is little information on the relationship between gender and palliative care, a comprehensive literature review was undertaken to analyse this relationship and to inform the development of a gender review framework for the project. In addition, a rapid appraisal was conducted among patients and caregivers in Zambia and Zimbabwe.

The policy review tool was used to review national policies and related documents in the ten southern African countries, including:
- National aids strategies;
- National cancer plans;
- National palliative care policies;
- National health policies;
- National gender policies;
- National home-based care policies;
- Essential drug lists; and,
- Maternal and child health care and reproductive health policies.

The review of these documents aimed to identify opportunities, gaps, strengths and gender issues that affect the integration of palliative care within policy, and assess the extent of integration. Therefore, it was important to develop a tool that would enable APCA to capture this information in a standard format. The primary aim of the tool was to enable reviewers to assess and review the type of language provided in each policy, and whether the language could be strengthened in favour of palliative care provision.

The review found an overall lack of inclusion of palliative care in policy documents. For most countries in the region, there is no mention of palliative care as an important aspect of care for people with life-threatening illnesses. In Zimbabwe, only one of the documents specifically addresses the need for palliative care. The World Health Organization (WHO) definition is not mentioned in any of the documents that were reviewed.

In Malawi, palliative care is given low recognition, and only one of the documents mentions palliative care (without any proper definition). In the DRC, the reviewed documents focus predominantly on HIV and AIDS care and associated services. While home-based care and holistic care are mentioned, these are not based on the WHO definition of palliative care and pain management does not feature.

Namibia is making strides in addressing the need for palliative care, and has embarked on integrating palliative care into the overall national health infrastructure, especially in more recent national
documents. However, there is a place for palliative care in all documents related to the care and protection of patients with life-threatening conditions and their families.

In general, all the documents from the ten countries would be suitable for varying levels of palliative care integration. A general but clear definition needs to be provided, along with relevant insertion of palliative care strategies as appropriate. It is important at all levels to emphasise that the family and the patient are the unit of care. Clear policy statements about the right to palliative care and pain control would reinforce the role of palliative care in mainstream health systems.

With regard to gender issues, all the documents could benefit by a broader understanding of gender, including sexual minorities. A greater emphasis on the role of men as caregivers would be appropriate. None of the documents addresses domestic violence in any detail, although some do refer to the issue.

In Angola, DRC, Lesotho, Malawi, Namibia, Swaziland and Zambia, opioids are not mentioned in much detail in the documents. The fact that pain relief is a basic human right and that unrelieved pain greatly impacts on quality of life means that there is a need to address the issue of availability and accessibility of opioids (particularly oral morphine), and to define how these medicines should be controlled across all levels of health care. In Mozambique, opioids are also not addressed, although there is a commitment to international human rights and best practice, which can assist the integration of palliative care, pain management, availability of opioids and their usage. In Botswana, all the reviewed documents mention morphine, but there is no evidence of laws and regulations regarding importation, transportation, prescription or storage.

All the reviewed documents fail to address the issue of opioid use adequately, and do not recognise the ethics of pain-relief. A statement on the right to a pain-free death would inform ethical considerations. There is minimal acknowledgement of ethics, human rights, anti-discrimination issues and confidentiality. The documents would benefit from linking human rights in general to the right to health care (including pain-control) in particular.

**Given the above findings, APCA makes the following recommendations:**

- Palliative care (as defined by WHO) should be integrated into policies and documents as appropriate, referencing the needs of women, children, vulnerable populations, minorities and all who require a holistic approach to living with life-threatening illnesses;
- A commitment to human rights needs to be explicit in policy and programme documents to make clear the link between the promotion of strategies and activities, and the daily lives of individual people;
- Safe and consistent opioid supplies need to be guaranteed – the relevant policies should detail the steps taken by the authority concerned (the national competent authority) for procurement and supply of pain-relieving drugs, particularly oral morphine, which might entail a review of the current rules and regulations regarding the use of opioids to ensure that there is increased availability and access to such medicines for patients who need them;
- The ministry of health in each country should be encouraged to consider developing national guidelines for the use of opioids, in line with international recommendations, to ensure the safe and effective use of opioids; and,
- An expanded understanding of gender issues to embrace sexual minorities is imperative if the HIV epidemic is to be addressed comprehensively, while risk behaviours of people who have concurrent and multiple sexual partners need to be debated without prejudice or judgement so that all people at risk are able to access care.
INTRODUCTION
I. Introduction

The need for effective palliative care service provision across Africa has never been more important. In 2009, UNAIDS estimated that there were 33.3 million people globally affected by HIV and AIDS, and noted that sub-Saharan Africa bears an inordinate share of the global HIV burden. Although the rate of new HIV infections has decreased, the total number of people living with HIV continues to rise. Sub-Saharan Africa has more women than men living with HIV. The estimated 1.3 million people who died of HIV-related illnesses in sub-Saharan Africa in 2009 comprised 72 percent of the global total of 1.8 million deaths attributable to the epidemic. Moreover, cancer rates in Africa are expected to grow by 400 percent over the next 50 years. The World Health Organisation (WHO) estimates that there are more than 0.5 million annual cancer deaths in Africa, and that by 2020 seventy percent of new cancer cases will be in the developing world. For the overwhelming majority of Africans who currently endure these and other progressive life-limiting illnesses, access to culturally appropriate holistic palliative care (that includes effective pain management) is at best limited, and at worst non-existent. Consequently, the need for an effective public health approach to palliative care service provision across Africa is a priority. The most beneficial way of achieving this is through the integration of palliative care into existing health care systems.

The WHO has advanced an enhanced model that states that for the public health approach to work there must be in place: appropriate policies; adequate drug availability; education of health professionals; and, implementation of palliative care at all levels. In many African countries, palliative care is not yet integrated into the national policies, so public health access is not available to the majority of those who require palliative care. The African Palliative Care Association (APCA), through funding from the Open Society Foundations (OSF) International Palliative Care Initiative (IPCI) and the Open Society Initiative for Southern Africa (OSISA), embarked on a project which aimed to review national legislation and policy documents and implementation strategies (including national health plans and strategies, HIV and AIDS strategies, home-based care plans, essential drug lists and policies, and other relevant documents) across ten African countries to identify and assess the opportunities, gaps, strengths, weaknesses, and gender issues that can be addressed to support palliative care scale-up at the national level. The countries included in the review were Angola, Botswana, DRC, Lesotho, Malawi, Mozambique, Namibia, Swaziland, Zambia, and Zimbabwe.

The review was undertaken using a review tool that was developed using existing information on policy, gender issues, and palliative care. While a great deal has been documented on the effects of policy on palliative care development, there is little information on the relationship between gender and palliative care. In view of this, a comprehensive literature review was undertaken to analyse this relationship and to inform the development of a gender review framework for the project. In addition, and in order to represent the beneficiaries’ needs and perspectives, a rapid appraisal was conducted among patients and caregivers. The information acquired from the rapid appraisal and the literature review was used to inform the development of the policy review tool.

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OVERVIEW OF THE LITERATURE
REVIEW AND THE RAPID APPRAISAL
2. Overview of the literature review and the rapid appraisal

A literature search was undertaken around the issues that exist within palliative care policies regarding gender. The following terms were used as the search criteria for this work:

- Gender and palliative care;
- Gender sensitivity within hiv and aids;
- Palliative care issues for women and men;
- Palliative care issues for boys and girls;
- Hiv and aids and women and men;
- Hiv and aids and children (boys and girls);
- Gender and cancer with men; and,
- Gender and cancer with women.

For the rapid appraisal, APCA worked with key contacts in Zambia and Zimbabwe to review the perceived barriers that policy and gender issues pose for the advancement of palliative care. It was envisioned that the results of the literature review and the rapid appraisal would be used to develop an evidence-based policy and gender review guideline that could be used to review policy documents. The methodology for the appraisal was mainly through focus group discussions (FGDs) and key informant interviews (KIIs) using data collection protocols developed by APCA based on information gathered from the literature review.

The rapid appraisal FGD participants were drawn from four sites in each country, and included clients accessing care and health providers. KIIs were held with policy-makers, health workers, institutional managers, and leaders of non-governmental organisations (NGOs) familiar with gender and palliative care issues. A representative mix of rural and urban, HIV and non-HIV or cancer, and NGO and government was sought.

Qualitative analysis was undertaken by thematically coding all discussions and interviews in line with project objectives. The findings of the appraisal were crucial in the development of the policy review tool, which was used to review national policies and related documents in each of the ten countries.

Highlights of both the literature review and the rapid appraisal were as follows:

- The rapid appraisal indicated that women access care earlier, although some of the literature indicates that men in fact access care earlier. The same conflicting results were evident for non-adherence to treatment and drop-out rates. The difference in results may be due in part to different methodologies reflecting anecdotal versus rigorous scientific research, or may indicate regional differences.

- Access to care seemed not to be linked to gender; men and women perceived their access to be the same and said that service provision did not differ in any way. Domestic violence was not considered to be an impediment to access to care. Gender minorities were highlighted in both the rapid appraisal and the literature review as being ignored and neglected. This has significant implications for the spread of HIV and constitutes a major impediment to the uptake of palliative care.
Both the rapid appraisal and the literature review confirmed that females mainly pay the price for care work, and that this is largely unpaid and unrecognised. Moreover there was a clear expression of exhaustion, helplessness and growing resistance on the part of primary carers. An important finding of the rapid appraisal was that there is no effective supervision of primary or secondary caregivers, who are left unsupported in terms of effective medication, equipment, and emotional support. In contrast, there appears to be a continuing perception that home-based care is the best option for managing the huge burden of HIV on the continent, and this approach depends on a belief that extended families (and communities) are willing to absorb the burden of chronic illness, dying and bereavement, especially in rural areas.

The non-availability of opioids remains a serious impediment to the expansion of palliative care, but just as serious appears to be the lack of education and awareness on the part of health providers about palliative care in general and pain control in particular.

The emphasis on developing policies to facilitate integration of palliative care into health systems needs to be repeated in implementation strategies in order to minimise the gap between formal instruments and practical implementation.

The importance of quality training, especially of caregivers, is one of the most significant results of the rapid appraisal and literature review. The spectre of patients left without adequate pain control or counselling is distressing for anyone involved with health care, and is unacceptable given that knowledge of palliative care is available. Building palliative care capacity in health centres and in the home needs to be a priority if Africa is to manage the HIV epidemic in any meaningful way.

Expanding availability and accessibility of pain medications in urban and rural areas is necessary to help patients benefit from good palliative care. Advocacy is required to expand policies enabling nurse prescribers to ensure that pain management in the home setting becomes a reality. The emphasis on home-based palliative care in both Zambia and Zimbabwe is severely at odds with the reality of no effective pain control at home.

Many of the obstacles to palliative care can be traced to the fact that it is not integrated fully into mainstream health systems. Commitment to training adequate numbers of health workers and secondary caregivers and ensuring that these cadres are backed up by transport facilities, drug re-supplies and links with nutritional support would probably only be viable once palliative care has an official place in the ministries of health.

It is vital to address the needs of marginalised populations who have a limited voice in requesting help. As HIV is sexually transmitted, it is necessary to address without discrimination the risk behaviours of those who have multiple partners or who engage in high-risk practices. Likewise the needs of prisoners, the physically and mentally disabled, and the aged are deserving of greater attention. Training is required to enable practitioners to incorporate the needs of minority groups into their assessments as a matter of course.
THE REVIEW PROCESS

3
3. The review process

The review was undertaken using a review tool developed using the information gathered from the literature review and the rapid appraisal. However, before the tool was developed it was important to agree on standard definitions of terms.

3.1 Standard definitions

For the sake of consistency, a number of key terms were defined (with examples) to ensure that their meanings were clearly understood by those undertaking the review.

Policy
A policy is typically a deliberate plan of action to guide and achieve rational outcomes. Policies differ from rules or laws. While laws can compel or prohibit behaviours, policies guide actions and oblige governments to support issues at the national level.

Example of a policy: National Health Policy.

Law
Law is a system of rules, usually enforced through a set of institutions. It shapes politics, economics and society in numerous ways, and serves as the primary social mediator in relations between people. Legal systems elaborate rights and responsibilities in a variety of ways. Law also raises important and complex issues concerning equality, fairness and justice.


Implementation guidelines
Implementation guidelines are documents that seek to guide the implementation of national policies.

Example of guidelines: National Health Strategic Plans.

Gender
Gender is defined as ‘the relations between men and women, both perceptual and material. Gender is not determined biologically, as a result of sexual characteristics of either women or men, but is constructed socially. It is a central organising principle of societies, and often governs the processes of production and reproduction, consumption and distribution’ (FAO, 1997).

Despite this definition, ‘gender’ is often misunderstood as being the promotion of women’s agendas only. However, gender issues focus not only on women but on the relationship between men and women, their roles, their access to and control over resources, division of labour, interests and needs. Gender relations affect household security, family well-being, planning, production and many other aspects of life. Gender relations are the ways in which a culture or society defines rights, responsibilities, and the identities of men and women in relation to one another.
DEVELOPING THE REVIEW TOOL
4. Developing the review tool

4.1 Introduction

The key aim of the tool was to enable reviewers to assess and review the type of language used in each policy, and whether the language could be strengthened in favour of palliative care provision. In addition it was important to assess and review how specific clauses could be amended to favour palliative care, and to assess opportunities within the policy through which palliative care could be incorporated.

APCA, in collaboration with consultants from Makerere University School of Public Health and a palliative care consultant from Zimbabwe, used information generated from existing literature and from rapid appraisals conducted in Kenya, Uganda, Zambia and Zimbabwe to identify different domains and to draft questions that would be used to assess each of the domains identified. Through several consultation processes the questions were reviewed and revised until 22 questions were identified under five domains.

Once the final draft was ready, the tool was reviewed by key partners including IPCI (OSF), OSISA, OSIEA, the Pain and Policy Study Group (PPSG), Family Health International (FHI), and other palliative care experts.

4.2 The document review tool

The review tool (please see www.africanpalliativecare.org/policywork) has pre-determined questions under five key thematic domains underpinned by the following principles:

- easy to use;
- structured with clear guidelines so that different people using the same tool will derive the same answers;
- written in an Excel spreadsheet format with drop-down menus (where appropriate) for ease of use and to assist with easy collation of information;
- sufficiently comprehensive to address the key issues, but not unwieldy;
- arranged around specific domains developed to provide consistency for the reviewers and based on the information generated from the literature review and the rapid appraisal, including:
  - general issues
    - document development
    - ease of implementation
    - language
    - inclusivity
  - gender issues
  - palliative care issues
  - legal and human rights issues
  - legal issues around opioid availability.

This tool was accompanied by clear instructions and relevant definitions to ensure that the review process was undertaken in a consistent manner by multiple reviewers. The tool was pretested using two different national documents by three different reviewers. This exercise was very important as it highlighted key areas in the tool that needed to be refined and reviewed before it was considered to be a final document and the review took place.
4.3 Overview of the tool domains

The review tool is split into nine key sections, each with a specific information focus.

4.3.1 Section 1a: Domain 1: Document development
Under this domain the reviewer was expected to assess whether there was a rationale to the
document (be it policy, strategy or otherwise), looking at whether it is a response to an identified
need, and if there is evidence of that need. In addition, the reviewer was expected to assess the
document development process to examine whether there was wide consultation with a range of
stakeholders (including clients, affected communities, service providers, etc.) and with a range of
government ministries (health, agriculture, gender, finance, etc.). This is important as it
demonstrates the documents’ ownership, and that could influence its implementation.

4.3.2 Section 1b: Domain 1: Document ease of implementation
The questions under this section relate to the implementation of the document and seek to
understand what the individual policies are which have given rise to the strategies or activities
described in the document. It looks at the level of practical information available on how the
policy statements are to be realised, or (at a minimum) reference to other existing documentation,
or future planned guidance on how to implement the policy. Strategies being looked for include
evidence of a monitoring and evaluation strategy or commitment of the government to financially
support its implementation. This then relates to the clarity of the document and the use of language
which encourages implementation, such as the use of simple terms and the inclusion of a glossary
where necessary.

4.3.3 Section 1c: Domain 1: Language
The documents were reviewed for evidence of translation which would make them more accessible
to all stakeholder groups in the country. If the document had been translated but this was not
evident, then a recommendation was provided but no assumptions were made. The language used
was reviewed for evidence that the document had been written in active and committal language
(such as “The government will” or “must” instead of “The government will consider” or “may” etc.).

4.3.4 Section 1d: Domain 1: Inclusivity
Inclusivity relates to the groups of people that are mentioned or addressed by the documents.
This includes evidence of inclusivity across ages (i.e. children, adolescents and adults), genders,
diseases (particularly important for generic health documents), ethnic groups, religious groups,
sexual orientations, and special needs or neglected groups (e.g. prisoners, refugees).

4.3.5 Section 2: Domain 2: Gender
The documents were reviewed for evidence of gender-neutral terms, including he/she, or other
generic terms such as ‘they’, ‘them’, ‘the client’, ‘the patient’. It is important for there to be key
statements relating to gender to give a general understanding of the concept. In view of this, the
reviewer looked for evidence that the culturally accepted roles and responsibilities of men and
women at community level are identified, and the implications of these on both men and women
are recognised. Gender stereotypes around socially expected roles of men and women were
reviewed to see if they were reinforced throughout the document or if there was a commitment to
counter them. It is also important for gender-based violence (GBV) to be understood and reflected
throughout the documents. The term ‘gender-based violence’ is used to distinguish violence that
targets individuals or groups of individuals on the basis of their gender from other forms of violence.
It includes any act which results in, or is likely to result in, physical, sexual or psychological harm.
GBV includes violent acts such as rape, torture, mutilation, sexual slavery, forced impregnation and
murder. It also defines threats of these acts as a form of violence.
4.3.6 Section 3: Domain 3: Palliative care
Each document was reviewed to assess whether there is any inclusion of palliative care or equivalent terms, such as end-of-life or terminal care. The reviewer then looked for key areas where palliative care could be integrated within the document, such as using committal language, including and referring to the definition of palliative care, and identifying components of palliative care (such as physical, spiritual, emotional and social pain) to indicate a holistic approach to care. The document was then reviewed for information relating to the importance of drug availability, including reference to the essential drug list or its equivalent, the need for palliative care training and skills development, and a description of how care is to be provided through an inter-disciplinary approach. It is very important to focus on who will benefit from the care and access at different levels of care for the patient. This needs to be reflected within the document as an implementation strategy, alongside a monitoring plan and the identification of stakeholder involvement and a responsible body coordinating the care in country. The policy document needs to clearly reflect the legal and ethical issues within palliative care, including any issues around confidentiality and stigma. The relief from pain as a human right is a key statement, and each document was reviewed in this light.

4.3.7 Section 4a: Domain 4: Opioids control
A review of the reference to opioid control was completed in relation to whether opioids are controlled drugs, and the rules and the controlling bodies involved in this. The document was then reviewed for reference to tax law related to the importation and movement of drugs, particularly with regards to whether drugs are tax exempt, and who is liable to pay the tax if not (i.e. providers or patients).

4.3.8 Section 4b: Domain 4: Opioids practice
Evidence and explanations of which disciplines are allowed to prescribe opioids (in particular morphine) were reviewed, specifically looking at which health disciplines are allowed to prescribe each category of opioid, and which outlets are allowed to dispense opioids. The documents were then reviewed with reference to pharmacy regulations and the guidelines that are in place, including the professional codes and standards regarding opioid use.

4.3.9 Section 4c: Domain 4: Opioids and human rights
Relief from pain is a human right and this needs to be reflected within policy documents. The review continued to look for references to patient confidentiality issues, handling of personal data and stigma, and anti-discrimination issues.

4.4 Target countries
The countries that were included in the review were Angola, Botswana, DRC, Lesotho, Malawi, Mozambique, Namibia, Swaziland, Zambia, and Zimbabwe. The choice of countries was based on the level of palliative care developed in each of the countries, and the fact these countries have well development HIV and AIDS programmes funded by OSISA. It was hoped that the document review would provide a point of entry for technical assistance to develop palliative care in the ten countries. In each country, national policy documents, strategies, and implementation guidelines were identified and reviewed using the evidence-based review tool developed for the project. Table1 shows the list of documents reviewed in each country.
### 4.5 Table 1: Documents reviewed in each country

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<th>Strategies</th>
<th>Guidelines</th>
<th>Implementation documents</th>
<th>Others</th>
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<td>Angola</td>
<td>Regulation for HIV/AIDS in the workplace, professional training and laws governing first jobs, 2009</td>
<td>National Strategic Plan for the control of Sexually Transmitted Diseases and HIV/AIDS, 2007 to 2010</td>
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<td>Lesotho</td>
<td>National HIV and AIDS strategic plan, 2006 – 2009</td>
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### Document Table

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<tr>
<th>Country</th>
<th>Policies</th>
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<td>National Medicines policy (2nd edition) 2010</td>
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<td>National Health Policy, 2006</td>
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<td>Zambia</td>
<td>National Gender Policy, 2005</td>
<td>National Health Strategic Plan 2006-2010</td>
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<td>Standard treatment guidelines, essential medicines list &amp; essential lab supplies for Zambia, 2009</td>
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<td>National HIV/AIDS/STI/TB Policy, 2000</td>
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<td>National policy on HIV/AIDS for the Republic of Zimbabwe, 1999</td>
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Following the review of documents in each country, results were presented to selected stakeholders. The aim of these presentations was to present the review findings and to seek input from local stakeholders. In addition, recommendations for integration of palliative care at national...
level were given to stakeholders in each country.

4.6 Figure 1: Project flow

1. Rapid appraisal and literature search
   - Conducted in Uganda, Zambia and Zimbabwe
   - The aim is to inform the development of the tool that would be used to review legislation, gender and policy issues around palliative care.

2. Tool development
   - Development of a comprehensive tool that covers all three areas (i.e. legal, gender and policy) that can be used in each of the countries to undertake the review.

3. Policy review
   - A review of documents in each of the identified countries using the tool and the accompanying guidelines

4. Roundtable discussions
   - Roundtable discussions to discuss the draft country reports and make recommendations in the IPCI/OSISA project countries

5. Project reports
   - Project Reports: Literature review and rapid appraisal report, consolidated policy review report and ten individual country reports.
4.7 Documents reviewed

The following documents were reviewed following authorisation from the Permanent Secretary within the Ministry of Health and other relevant bodies in each of the ten project countries:

- National AIDS strategy;
- National cancer plan;
- National palliative care policy;
- National health policy;
- National gender policy;
- National home based care policy;
- Essential drug list; and,
- Maternal and child health care and reproductive health policies.

Once received, the documents were assessed in line with the project brief, and the most appropriate three or four documents were reviewed for each country. In general, the collation of the documents from each country was easily achieved, although this was dependent on contacting the correct people and gaining the correct permissions to take the documents out of the country. Some of the project countries, such as Botswana, provided many documents, but a number of these were either in a draft form or were old and not considered to be current. Other countries, such as Mozambique and Angola, had very few documents that were relevant to the scope of the project, which limited the number that could be reviewed.

A team of staff and consultants worked on reviewing the documents for each country. Once the review was completed, the results were sent to a central point where they were consolidated into a series of worksheets and tables to show the main findings. At this stage, a draft country report with the findings, recommendations and conclusions from the documents reviewed was developed for each of the ten project countries. These reports were used to form the basis of the stakeholders roundtable meeting mentioned in the project flow (Figure 1).

4.8 Stakeholder meetings

After the review was completed, a stakeholder meeting was held in each country to discuss the results, to seek feedback on the findings, to build a consensus on the results, and to discuss opportunities for the integration of palliative care (including areas such as opioid accessibility, human rights issues and gender) into current health-related policies. These meetings were also an opportunity to introduce the participants to the concept of palliative care.
GENERAL FINDINGS
5. General findings

The findings presented below are from three key domains: palliative care, opioid use and gender. From the documents reviewed, it was clear that in all ten countries there is very little inclusion of palliative care, gender or the right to pain relief in national legislation. The following summarises the general findings and conclusions. More detailed information (including findings from other domains) is available in the individual country reports.

5.1 Palliative care

The review found an overall lack of inclusion of palliative care in policy documents. For countries such as Angola, Botswana, Lesotho, Mozambique, Swaziland, and Zambia there is no mention of palliative care as an important aspect of care for people with life-threatening illnesses.

In Zimbabwe, only one of the documents specifically addresses the need for palliative care as an integral part of care plans for people living with cancer. The WHO definition is not mentioned in any of the documents that were reviewed, although the Zimbabwe cancer control programme refers to palliative care with appropriate understanding of its holistic and multidisciplinary nature. The HIV and AIDS policy recognises the need for care for terminally ill people at home, but misses an opportunity to identify the value of palliative care for this purpose.

Namibia is making strides in addressing the need for palliative care, and has embarked on integrating palliative care into the overall national health infrastructure, especially in more recent national documents. The National HIV Policy and the National Strategic Framework clearly articulate the need for palliative care, but there is a place for palliative care in all documents related to the care and protection of patients with life-threatening conditions and their families.

In Malawi, palliative care is given low recognition, and indeed it is only the National Community Home Based Care Policy and Guidelines that mentions palliative care (without any proper definition).

In the DRC, the reviewed documents focus predominantly on HIV and AIDS care and associated services. While home-based care and holistic care are mentioned, these are not based on the WHO definition of palliative care, and pain management does not feature. Much of the focus for palliative care is on the care of the dying.

In general, all the documents from the ten countries would be suitable for varying levels of palliative care integration. A general but clear definition needs to be provided, along with the relevant insertion of palliative care strategies as appropriate. It is important at all levels to emphasise that the family and the patient are the unit of care.

Where health is the main focus of the policy, there is increased scope for expanding the document to incorporate the following issues:

- palliative care definitions;
- discussion of possible models and place of care delivery;
- clear guidelines about who should be the recipients of care;
- who should deliver care and how palliative care training is to be provided; and,
- how pain relief can be ensured.
Clear policy statements about the right to palliative care and pain control would reinforce the role of palliative care in mainstream health systems.

The value of palliative care to any policies relating to HIV should also be highlighted.

5.2 Gender

With regard to gender issues, all documents would benefit from a broader understanding of gender, including sexual minorities. A greater emphasis on the role of men as caregivers would be appropriate. None of the documents addresses domestic violence in any detail, although some do refer to the issue. The documents are careful to use gender-neutral terms (e.g. “people”, “adults”), which would allow for additional detail to be added embracing the needs of sexual minorities.

5.3 Opioids

In Angola, DRC, Lesotho, Malawi, Swaziland, Namibia and Zambia, opioids are generally not mentioned in much detail in the documents. The fact that pain relief is a basic human right and that unrelieved pain greatly impacts on quality of life means that there is a need to address the issue of availability and accessibility of opioids (particularly oral morphine), and to define how these medicines should be controlled across all levels of health care. In Mozambique, opioids (including their control, practice and tax-related law related to the movement of drugs) were also not addressed, although there is a commitment to international human rights and best practice, which can assist the integration of palliative care, pain management, availability of opioids and their usage. In Botswana, all the reviewed documents mention morphine as a drug (amongst others) being used or on the essential drug list, but there is no evidence of laws and regulations regarding importation, transportation, prescription or storage.

All the reviewed documents fail to address the issue of opioid use adequately, and do not recognise the ethics of pain-relief. A statement on the right to a pain-free death would inform ethical considerations. Many of the documents do not discuss tax and prescribing regulations. All documents would be enhanced by recognising the need for balance between drug safety and making pain-control accessible to all who need it. There is minimal acknowledgement of ethics, human rights, anti-discrimination issues and confidentiality. The documents would benefit from linking human rights in general to the right to health care (including pain control) in particular.

5.4 Recommendations

The African Palliative Care Association makes the following recommendations:

- Palliative care (as defined by WHO) should be integrated into policies and documents as appropriate, referencing the needs of women, children, vulnerable populations, minorities and all who require a holistic approach to living with life-threatening illnesses;
- A commitment to human rights needs to be explicit in policy and programme documents to make clear the link between the promotion of strategies and activities, and the daily lives of individual people;
- Safe and consistent opioid supplies need to be guaranteed – the relevant policies should detail the steps taken by the authority concerned (the national competent authority) for procurement and supply of pain-relieving drugs, particularly oral morphine, which might entail a review of the current rules and regulations regarding the use of opioids to ensure that there is increased availability and access to such medicines for patients who need them;
- The ministry of health in each country should be encouraged to consider developing national guidelines for the use of opioids, in line with international recommendations, to ensure the safe and effective use of opioids; and,
An expanded understanding of gender issues to embrace sexual minorities is imperative if the HIV epidemic is to be addressed comprehensively, while risk behaviours of people who have concurrent and multiple sexual partners need to be debated without prejudice or judgement so that all people at risk are able to access care.

APCA’s role in ensuring that these recommendations are implemented begins with advocacy for the integration of palliative care at all levels of policy-making, based on a public health approach. APCA is currently seeking funds to support this pioneering work as policy development is crucial for palliative care scale-up across Africa.
References


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About APCA

The African Palliative Care Association (APCA) is a non-profit making pan-African membership-based organisation which was provisionally established in November 2002 and formally established in Arusha, Tanzania, in June 2004. Acknowledging the genesis of modern palliative care within the United Kingdom, APCA strives to adapt it to African traditions, beliefs, cultures and settings, all of which vary between and within communities and countries on the continent. As such, in collaboration with its members and partners, APCA provides African solutions to African problems, articulating them with what is the recognised regional voice for palliative care.

APCA’s vision is to ensure access to palliative care for all in need across Africa, whilst its mission is to ensure palliative care is widely understood, underpinned by evidence, and integrated into all health systems to reduce pain and suffering across Africa. APCA’s broad objectives are to:

- Strengthen health systems through the development and implementation of an information strategy to enhance the understanding of palliative care among all stakeholders;
- Provide leadership and coordination for palliative care integration into health policies, education programmes and health services in Africa;
- Develop an evidence base for palliative care in Africa;
- Ensure good governance, efficient management practices and competent human resources to provide institutional sustainability;
- Position palliative care in the wider global health debate in order to access a wider array of stakeholders and to develop strategic collaborative partnerships, and;
- Diversify the financial resources base to meet APCA’s current funding requirements and to ensure the organisation’s future sustainability.

www.africanpalliativecare.org