One health system, many avenues for relieving pain and suffering
9.67 million people are in need of palliative care across the continent

For the last seven years, the African Palliative Care Association (APCA) has been working to address the alleviation of pain and suffering – physical, emotional, social and spiritual – on behalf of millions of patients across the continent.

As we've done so, we've seen how the relief of pain and suffering for an individual ripples through the diverse layers of health systems, each of which carries a key to restoring the rights and dignity of those who are suffering.

In Africa, the need for palliative care is immense, but largely unmet. The World Health Organization (WHO) estimates that approximately 9.67 million people are in need of it across the continent. Faced with this stark reality, we at APCA have established that the task of relieving pain, suffering and restoring dignity for millions of African patients needs to be addressed by strengthening the health systems that the majority of the continent's patients rely upon.

'One health system, many avenues for relieving pain and suffering' is therefore the theme of this report. We believe that the path toward strengthening health systems for patients has to be addressed through policy integration, information sharing, strengthened skills and education, and an increased evidence base to enrich the sustainability of our work.

To this end, APCA launched a ten-year strategic plan in 2011, with a mission to ensure palliative care is widely understood, integrated into health systems at all levels, and underpinned by evidence in order to reduce pain and suffering across Africa.

The impact of this plan has already been evident in 2011, as APCA worked to encourage governments across Africa to uphold patients' rights through the integration of palliative care into national health policies. This year, Swaziland will be launching a national palliative care policy developed with support from APCA and other stakeholders; Malawi initiated the process of developing a palliative care policy; and in Rwanda a palliative care policy was launched in April which will be supported by an adopted version of the APCA Standards for Providing Quality Palliative Care Across Africa.

APCA has also been working to mitigate the widespread lack of understanding of what palliative care actually is as well as its benefits. Through the launch of a toolkit to promote successful advocacy, we advanced our aim to raise awareness around palliative care across Africa. APCA has also been building the capacity of health professionals through curriculum integration and has scaled up information-sharing through a new website launch and the identification of new partners in the public and health sector to be involved in palliative care.

To increase and coordinate the evidence base for palliative care, we're pleased to announce the establishment of the African Palliative Care Research Network (APCRN), through which we believe strong research and evidence will contribute to the sustainability of palliative care and its impact on the continent. As we branch out to establish new partnerships, we are confident that the journey toward health systems strengthening will continue to enrich both caregivers and patients benefiting from improved care.

We are thankful to our donors, partners and friends who have locked arms with us to ensure that palliative care is mainstreamed in such a way that patients in need feel the impact of our efforts. It is our pleasure to present this report highlighting some of APCA's key accomplishments over 2010/11 toward achieving this aim.

Thank you to Hospice Africa Uganda, the Machakos Hospital Palliative Care Unit and Nairobi Hospice for enabling us to illustrate aspects of palliative care delivery in this report. The commitment and drive shown by these organisations are vital in helping attain APCA's goal of palliative care service delivery for all in need throughout Africa.

Mary Masi, aged 60, receives palliative care services for cancer of the cervix treatment at Kenya's Machakos Hospital (front cover).
APCA works to bring relief from unnecessary physical and psychological suffering to patients living with life-limiting illnesses such as cancer and HIV and AIDS, and to their families and carers. We promote holistic palliative care, focused on recipients’ needs – from pain and symptom management, to support with practical problems, emotional needs and spiritual issues.

APCA’s Aims

How We Work
APCA helps to expand service provision, builds capacity locally and facilitates networking that will fuel palliative care development. We advocate for a public health approach, founded on appropriate government policies, adequate drug availability, the education of health professionals and the implementation of palliative care throughout society. Underpinned by four strategic drivers, our key areas of work include:

Increasing awareness for palliative care
APCA has been working to counter the widespread lack of awareness in Africa around what palliative care actually is as well as its benefits. We work with policy makers, hospital management teams, deans of universities, community leaders, caregivers and patients, as well as the media, to ensure that information around palliative care is accurately shared with those who need it.

Enhancing palliative care integration
Education and training
We promote palliative care education for doctors, nurses, social workers and other members of the multi-disciplinary palliative care team. As well as working with medical schools and universities to develop curricula, we produce a comprehensive range of tools and manuals to help promote the delivery of top quality care in Africa. We train people in their use and build their capacity to train others in the effective use of these tools and manuals in their localised context.

Changing policy
APCA advocates directly with governments, encouraging them to include palliative care in national health policies, to resource it adequately and to allow the right medication to reach those who need it (in many African countries, morphine and other opioids classified by the WHO as essential for effective pain control are not legally available for medical use). We support national palliative care associations in their advocacy, both directly and through tailor-made resources.

Increasing evidence for palliative care
APCA supports evidence-based work that advances the scientific knowledge base of palliative care in Africa, as well as service delivery. We carry out research into palliative care needs and practices, disseminate our learning widely, and monitor and evaluate all our work. We also train palliative care providers to do the same, using specially developed tools such as the APCA African Palliative Outcome Scale (POS) for measuring the effectiveness of palliative care.

Sustainability and capacity building
We offer technical support to national palliative care associations and care providers, helping them build both staff and institutional capacity to promote and deliver palliative care. As a membership organisation, we drive support for palliative care across and beyond Africa, building a dynamic community to create the momentum that will bring palliative care – the kind of care we’d all want for ourselves and our families – to everyone who needs it in Africa.

A multi-layered approach
In all these areas, we tackle the key issues from many different angles, from grassroots to government policy, so we can achieve maximum effectiveness in bringing about change. Among the most pressing challenges we currently face is drug availability. We can’t ignore the fact that excellent medications exist for the control of physical pain and other symptoms, and yet aren’t available to most people in Africa. In particular, we’re working to ensure that opioid painkillers – most commonly in the form of liquid morphine – are available to everyone in need.

Underpinning all this is APCA’s grassroots work through training and the media to create awareness among community volunteers and patients of the powers of modern pain medication and social support, and of the basic human right to a life free from unnecessary pain. By bringing people together on several levels - from policy makers and drug manufacturers, to healthcare professionals and community members - APCA makes a unique contribution towards the vision we all share that of an Africa where holistic palliative care reaches all who need it.

APCA’s stakeholders
APCA works to build effective linkages between all its key stakeholders, including: patients, their families and communities; carers (both family and volunteers); health care providers and educators; African governments, policymakers and decision-makers; its constituent members (both individuals and organisations); national palliative care associations, hospices and palliative care organisations; civil society groups; academic institutions; the media; governmental and non-governmental donors (both within and outside the continent), and the general public in a network of South-South and North-South partnerships.
‘I know that somewhere, somehow this morphine may reach either a friend or a relative who is in pain and make a difference in this person’s life and make a change probably in the entire family’s life.’

Rosemary Canfua
Senior Dispenser
Hospice Africa Uganda
We regard high-quality palliative care for all those in need as a human right. Our vision is of an Africa where everyone living with a life-limiting illness has access to such care.

Mainstreaming Policy

As APCA strives to ensure palliative care is incorporated into national policy frameworks across Africa, we keep the patient who benefits from these policies at the forefront of our efforts. The significance of a national policy framework means that palliative care services are budgeted for on a national level, trickling down to the patient who can then access palliative care services, available at their local health facility.

Our experience has shown that where palliative care has not been integrated into national policies and guidelines, there are significant barriers toward its implementation in health services and education programmes. Having a national policy steers services toward a point of reference for funding and accountability in implementing services according to defined standards at both public and private health facilities. A national policy also means that health educators can confidently integrate and prioritise palliative care at all levels and within all models of healthcare training.

If a national palliative care policy is in place, accompanied by relevant clinical guidelines and standards, both the patient and clinician can confidently challenge the quality of palliative care provision, thereby increasing accountability toward improved treatment that best serves the patient’s needs.

Supporting palliative care national policy development
APCA has taken several significant strides this year, yielding tangible outcomes, in supporting more African countries to integrate palliative care into their national policies.

In Kenya, the first national cancer control strategy was launched in 2011, with recommendations incorporated from APCA’s review of national policy documents in 2009 and with leadership from the Kenya Hospice and Palliative Care Association (KEHPCA). The strategy served as a milestone to tackle the country’s high cancer prevalence rate.

APCA supported Rwanda in becoming the first African country to have a stand-alone palliative care policy on the continent, supported in April 2011 by the launch of its national palliative care strategic plan and standards. We were pleased to provide technical assistance throughout the process - from drafting the policy, to providing input into its structure.

APCA’s Palliative Care Standards for Providing Quality Palliative Care Across Africa were adopted by the Rwandan Ministry of Health and we have been collaborating with the Minister of Health to support the implementation of the country’s new palliative care policy. We believe that one of the key ways in which policy implementation can be effected is through experiential learning through our study visit programmes. When the Rwandan Minister of Health authorised a study visit to Uganda for the Head of Non-Communicable Diseases and the Director of Medical Procurement and Distribution, this served as an important step toward sharing the intricacies of palliative care implementation at a national level and its implications for the national pain medication supply chain.

In Swaziland, APCA has provided technical support to the government in developing a national palliative care policy, which was passed by the Swaziland Cabinet and is due for launch before the end of 2011. Arising from the policy, the Ministry of Health has drafted national palliative care clinical guidelines with APCA’s technical support, and has plans to adapt APCA’s Palliative Care Standards for Providing Quality Palliative Care Across Africa. As a way of supporting policy implementation, APCA has included one of Swaziland’s public hospitals in its work around pain management and has sensitised the Ministry of Health Coordinator and the Mbabane Government Hospital’s leadership in palliative care service provision. Swaziland’s Minister of Health has confirmed his plan to undertake an experiential palliative care study visit to Uganda.

The process of developing a national palliative care policy has also been initiated in Zambia, where we are working closely with the Hospice Palliative Care Association of Zambia (HOSPAZ). Consultations have commenced with local stakeholders that include the Ministry of Health, palliative care service providers, HIV and AIDS and home-based care organisations, education institutions and local donors.

The Palliative Care Association of Malawi (PCAM) is advancing the policy development process with APCA’s technical support. To underpin their efforts, we sent the Chief Pharmacist of the Palliative Care Association of Malawi (PCAM) is advancing the policy development process with APCA’s technical support. To underpin their efforts, we sent the Chief Pharmacist of the Palliative Care Association of Malawi (PCAM) to Uganda for the Head of Non-Communicable Diseases and the Director of Medical Procurement and Distribution, this served as an important step toward sharing the intricacies of palliative care implementation at a national level and its implications for the national pain medication supply chain.

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APCA also completed a review of national policies across ten Southern African countries to assess the gaps, and opportunities that can be used to integrate palliative care into existing national policies and implementation frameworks. The review not only enabled APCA to develop a validated policy review tool, it also provided a comprehensive framework for advocacy among governments and policy makers in these ten countries.
Although the need for palliative care in Africa has never been greater, many millions of people who need it don't receive it. APCA was founded in 2004 to ensure they do.
Mainstreaming Information

APCA has been working to counter the widespread lack of awareness in Africa around what palliative care actually is as well as its benefits. We work with politicians, hospital management teams, deans of universities, community leaders, caregivers and patients, as well as the media, to ensure that information around palliative care is accurately shared with those who need it.

We believe that every person, at every level of healthcare delivery, has a unique role to play in raising awareness around palliative care with information sharing as an interwoven component into the fabric of healthcare provision. From doctor-to-patient communication on treatment options, to the education and training of doctors, nurses and caregivers, and through collaboration between organisations sharing best practices, each stakeholder plays an important part in improving the quality of services patients receive.

Driving change through APCA’s 2011-20 strategic plan
APCA launched a new ten-year strategic plan for the period 2011-20. The aim behind the plan is to ensure palliative care is widely understood, integrated into health systems at all levels, and underpinned by evidence in order to reduce pain and suffering across Africa. The beneficiaries of this strategic plan are the millions of people across Africa with life-threatening illnesses who are currently not accessing palliative care. Patients’ needs (rather than a disease focus) and strengthening systems, is therefore the focus of the plan, so that patients’ needs are ultimately met in an effective and affordable manner.

Advocating for change
This year, APCA produced an advocacy for palliative care toolkit to empower local palliative care champions across Africa to engage their policy makers, their local media, as well as donors, on why palliative care should be a priority component of health care. The toolkit was developed with input from advocacy and palliative care experts across Africa with the aim of supporting advocacy activities to increase access to pain and symptom relieving medicines for patients requiring palliative care.

Realising that palliative care necessitates a multi-disciplinary approach, APCA has been sensitising and training lawyers in Uganda to develop Information Education and Communication (IEC) materials and guides to meet the legal needs of palliative care patients.

In Malawi, we supported the production of information leaflets for community volunteers and family caregivers through the PCAM. By developing a referral tool, caregivers and patients in Malawi can now have access to legal support to address the legal challenges that often arise from a life-limiting illness.

Experience sharing: Central and Southern Africa
Through our study visit programme, we believe that experiential learning by policy makers is an effective way to raise awareness around palliative care. To this end, APCA supported a strategic study visit for a representative from the Ministries of Health in Rwanda, Tanzania, Zambia, Swaziland and the Democratic Republic of Congo to Uganda. During these visits, participants were introduced to palliative care delivery models and were exposed to supply chain management for pain-relieving medications.

Awareness raising: West and North Africa
This year, we particularly targeted the unique needs of West and North African countries in promoting advocacy around palliative care through the provision of technical support to newly formed national associations. These national associations are taking the lead in raising awareness around the importance of palliative care integration in their respective countries.

In July 2010, the National Palliative Care Association of Cote d’Ivoire was formed and will be officially launched in October 2011. In The Gambia, APCA supported the formation of an interim palliative care committee that will oversee palliative care development in that country and this committee could eventually develop into a national association. Cameroon launched their national palliative care association and meetings with the Minister of Health have been underway to raise awareness around the benefits of opioid availability for patients.

APCA small grants programmes
Through a partnership with the True Colours Trust Small Grants Programme, APCA has provided funds to organisations including hospices, non-governmental organisations and hospitals to support palliative care activities on the continent. Since the inception of this programme in 2009, a total of 36 organisations in 11 African countries have been empowered to provide palliative care services for children, to purchase medicines and equipment, and to undertake accredited palliative care training. With the aim of supporting nurses in furthering their skills for palliative care service provision, a two-year scholarship from the African Palliative Care Nursing Scholarship Fund was initiated in 2010 through a partnership between APCA and the Foundation for Hospices in Sub-Saharan Africa (FHSSA). The fund has benefited nurses from four African countries (Cameroon, Malawi, Nigeria, and Uganda) through educational courses, diploma programmes and bachelor degrees.

APCA also provided small grants to Cameroon, Ghana, Nigeria, and Sierra Leone with funding from AIDSTAR-One to support the implementation of palliative care advocacy plans. In Ghana, information-sharing consultations were held to educate policy makers and healthcare workers on the need for palliative care services and making oral morphine accessible for patients in need.

“Palliative care tries to narrow that gap between what the healthcare provider wants to give and what the person who comes for treatment wants to get.”
The scaling up of palliative care across the African continent demands not only an increase in the number of service providers via the public health system, but equally a demonstrable improvement in the quality of care provided to patients with progressive, life-limiting illnesses and their families. However, despite the reported need among care providers, the evidence base for health outcomes underpinning current palliative care service provision on the continent is inadequate. More specifically, there is minimal methodologically robust evidence measuring its impact upon its recipients.

Without such evidence, the beneficial impact of care provision can only be validated by anecdote, rather than rigorous proof. Hence, with existing clinical practices followed irrespective of whether or not they exert a positive outcome, the cost effectiveness of such interventions remain unknown and whatever good practices are not transferred across the continent. A final repercussion to the lack of evidence is that palliative care models from resource-abundant countries can be transposed without adaptation through evaluation to the African context.

Moreover, the absence of clear evidence means that key policy makers and funding agencies will not be persuaded to advocate for and support palliative care service delivery. For these reasons, APCA has been working to build an evidence-oriented infrastructure in Africa to measure the impact of palliative care initiatives.

Recently there has been recognition of the need to advance palliative care research on the continent, which has resulted in the formation of the African Palliative Care Research Network (APCRN). The APCRN is a long-term collaboration between African and international health researchers in an alliance that seeks to develop indigenous research capacity and, in part, demonstrate the impact of palliative care interventions.

To mitigate the absence of an instrument to measure palliative care outcomes, APCA, in collaboration with partners, developed the APCA African Palliative Outcome Scale (POS), which focuses on the WHO’s definition of palliative care, capturing physical, psychological, social and spiritual problems. The APCA POS has since been validated across diagnostic groups, countries, settings and languages and used in both quality improvement and research studies. Moreover, feedback on the tool from doctors and nurses who have used it has been very supportive, with providers perceiving it as an easy-to-use instrument that helps them undertake holistic assessments that entail discussing difficult issues with patients.

Research & Evidence

‘Palliative care in Africa is not new. It has been done in many formats and settings. However, an evidence base helps us to identify with confidence what works best when, where and how.’

Professor Elly Katahira
APCA Board Member and President,
International AIDS Society and Professor of Medicine at the College of Health Sciences, Makerere University in Kampala, Uganda

The development of the APCA POS usefully demonstrated the need for a comparable tool that is appropriate for use with children. Following a review that showed the lack of a multi-dimensional palliative care outcome tool capturing the needs and priorities of this age group and their families, APCA is in the process of piloting and validating the APCA African Children’s Palliative Outcome Scale (POS), a simple and brief outcome measure that uses patient-level indicators in routine clinical practice, in research, and across different diagnoses.

These tools are an important step forward in helping us measure the impact of palliative care services. Creating a strong evidence base through these instruments helps ensure that African patients and their families can receive proven quality services provided by a team that understands the value of measuring the impact of the care they offer.

Promoting quality services through strategic resources
APCA has developed resources used by healthcare practitioners to empower them to reach out to patients and manage their pain. These resources include the distribution of the Beating Pain: A Pocket Guide for Pain Management in Africa and its translation into French and Portuguese. The guide provides tips and guidance on assessing, measuring and managing holistic pain (physical, psychological, spiritual and social) and includes a section for children’s doses for pain-relieving medication.

As a result of a comprehensive review of palliative care curricula and training materials, we developed a curriculum review tool to help institutions delivering palliative care training review their curricula and training materials, ensuring they are in line with the APCA standards and competencies documents.

In order to assess the outcome of palliative care provided to patients with life-threatening conditions and their families, we developed the APCA African POS. This is a simple tool for measuring outcomes of care for patients receiving palliative care and has been validated across countries, settings and languages, and used in both quality improvement and research studies. The Guidelines for the Use of the APCA African Palliative Outcome Scale demonstrates the user through the steps of using the tool, including how to analyse and use the data for the improvement of patient care.

Advancing palliative care integration into a human rights framework
APCA participated in a side-event approved by the Human Rights Council, which was held as a parallel session during the 17th Session of the Human Rights Council meeting in 2011. The theme of the panel, ‘Access to palliative care: neglected component of the right to health’, served as a crucial advocacy opportunity to highlight an area of need in palliative care that the Council could address.

-reaching out through agenda-setting partnerships
APCA participated in the 9th Asia Pacific Palliative Care Conference, held in Penang, Malaysia, to exchange best practices and reach out internationally to partners who are working toward the same aims, often in resource-limited contexts.

In South Africa, APCA participated in the Africa Regional Dialogue of the Global Commission on HIV and the Law. For the first time, civil society organisations and representatives of governments from 27 African countries met to engage in dialogue on key issues and solutions for legal and human rights issues in HIV and AIDS. This meeting provided an entry point for APCA into such networks, and has since established collaborative relationships with various strategic organisations in attendance, such as the UNAIDS regional team, the East Africa Network of People Living with HIV (PLHIV) and various legal organisations in health.

Also in South Africa, APCA participated in an agenda-setting workshop on Caring for Women with HIV in response to the UN’s call for proposals to work with three marginalized communities - sex workers, women living with HIV, and lesbian, gay, bisexual, and transgender (LGBT) communities. APCA was pleased to present findings from a 10-country review on the policy landscape around palliative care.

‘Suffering patients have a right to the best palliative care, and we need solid evidence from good research to find out what this best palliative care is.’

Professor Lukas Radbruch
Member of the APCRN, Chair of Palliative Medicine, University of Bonn, Director of Department of Palliative Medicine, University Hospital Bonn, Director of Palliative Care Centre, Malteser Hospital Bonn/Rhen-Sieg

Research Out
APCA’s vision is to create an organisation that will promote palliative care on the continent in a way that is sustainable. We are committed to meeting our operational requirements through excellent human resource management, good corporate governance and adequate financial resources to sustain us in the short-, medium- and long-term. To build toward APCA’s longevity, the following initiatives have been launched this year that build strategic partnerships that promote palliative care across the continent.

Establishing a partnership framework
This year, APCA developed a cohesive, operational approach to direct partnership development, adding increased consistency in how partners are supported and/or brought into APCA’s work, and to provide the infrastructure necessary to ensure that critical partnerships are consistently nurtured and strengthened.

Sustainability through information, research and evidence
With information-sharing as a strategic priority in enhancing APCA’s sustainability, this year APCA launched a new interactive website to increase the profile of palliative care in Africa and among partners. The new website includes features such as a resource centre where APCA publications will be made available, as well as blogs, profile stories, a revamped social media presence and the promotion of online donations to sustain our work.

We believe that building a strong research and evidence base is paramount to the sustainability of palliative care and its impact on the continent. To increase and coordinate an evidence base for palliative care, we hope that through the establishment of the APCRN, a strong research and evidence base will contribute to the sustainability of palliative care and its impact on the continent.

“I’ve seen many people suffering in pain. I’ve seen close people die in dire pain. I said if there is a possibility to play a role in this I thought why not.”

Rosemary Canfua
Senior Dispenser
Hospice Africa Uganda
Financial Information

Where the money came from

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Where the money went

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We greatly appreciate the generous contributions of all APCA’s donors. Through their support we can continue to work for a future free from unnecessary pain and suffering for patients and their families.

American International Health Alliance
Foundation for Hospices in Sub-Saharan Africa
Friends in Global Health
John Snow International/AIDSTAR-One
Open Society Institute
Open Society Initiative for Eastern Africa
Open Society Initiative for Southern Africa
Pharmaceutical Research and Manufacturers of America
President’s Emergency Plan for AIDS Relief
PRISMA
The Commonwealth Foundation
The Diana, Princess of Wales Memorial Fund
The True Colours Trust
UK Department for International Development / Help the Hospices
USAID Malawi
USAID Namibia
USAID Southern Africa (Regional HIV/AIDS Programme)
USAID Tanzania
World Health Organization

Make a donation

All donations made to APCA, whether large or small, are greatly appreciated and will be used in a transparent, accountable and effective way to help reduce the suffering and improve the lives of people with life-limiting illnesses and their families across Africa.

We’re currently working towards being able to accept donations online. In the meantime, if you’d like to support APCA financially, please let us know at donate@africanpalliativecare.org and we’ll contact you with further details.

Thank you.
Join us to change lives.

Although the need for palliative care in Africa has never been greater, many millions of people who need it don’t receive it. APCA was founded in 2004 to ensure they do, and now works collaboratively with existing and potential care providers in more than 20 countries. Based in Kampala, Uganda, we are the recognised voice for palliative care in Africa, and the driving force for its development.

We regard high-quality palliative care for all those in need as a human right. Our vision is of an Africa where everyone living with a life-limiting illness has access to such care, restoring their dignity and quality of life, and delivered in an affordable and culturally appropriate manner.