



AFRICAN PALLIATIVE CARE ASSOCIATION ANNUAL REPORT 2013-14

INTEGRATING PALLIATIVE CARE



Helping to integrate palliative care into existing health systems across Africa.

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Acronyms



APCA	African Palliative Care Association
APCRN	African Palliative Care Research Network
APPF	African Pain Policy Fellowship
CDC	Centers for Disease Control and Prevention
HOSPAZ	Hospice and Palliative Care Association of Zimbabwe
HPCA	Hospice Palliative Care Association of South Africa
IEC	Information Education Communications
LGBT	lesbian, gay, bisexual and transgender
MoH	Ministry of Health
NCDs	non-communicable diseases
NGO	non-governmental organisation
PCAR	Palliative Care Association of Rwanda
PCAU	Palliative Care Association of Uganda
PCAZ	Palliative Care Alliance of Zambia
PMP	Performance Monitoring Plan (tool)
POS	Palliative Care Outcome Scale
TOT	training of trainers
TPCA	Tanzania Palliative Care Association
UGANET	Uganda Network on Law, Ethics and HIV/AIDS
WHA	World Health Assembly
WHPCA	Worldwide Hospice Palliative Care Alliance



At the heart of all of APCA's work are the patients and their friends, family and community. Here is a selection of patients who continue to inspire, educate and lead our work.



About APCA



The impetus for APCA's founding in 2004 originated at a meeting of 28 palliative care trainers from across the African continent, who met in Cape Town, South Africa, in 2002 and produced a declaration calling for the integration of palliative care into health care systems and national health strategies. APCA, a membership-based pan-African organisation, has its headquarters located in the capital of Uganda, Kampala.

OUR VISION

“Access to palliative care for all in Africa”.

OUR MISSION

To ensure that 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.

STRATEGIC OBJECTIVES

- 1 To develop and implement an information strategy on palliative care for all levels of stakeholders in Africa.
- 2 To provide leadership and coordination for palliative care integration into health policies, education programmes and health services in Africa.
- 3 To develop an evidence base for palliative care in Africa.
- 4 To develop and implement a financial sustainability framework for APCA.



OUR CORE VALUES

Our core values, reflected in the various interventions, decisions and relationships that APCA is involved with, are:

Collaboration:

We work collaboratively, by asking for and giving support and by sharing success with others.

Integrity:

We are honest, trustworthy and straightforward in all our dealings, and we use time, money and resources wisely.

Diversity:

We value others for their contribution, irrespective of personal differences, we provide equal access to opportunities and we discourage any form of unfair discrimination.

Respect:

We involve and listen to others, and show consideration and empathy for their emotional and physical well-being.

Excellence and quality:

We always strive to provide services that meet or exceed the needs, standards and timescales of our internal and external stakeholders, and always strive for excellence and quality in all areas.

Reliability:

We deliver what we commit to and keep our stakeholders informed of progress.

Social justice:

We strive to create an organisation that is based on the principles of equality and solidarity, that understands and values human rights, and that recognises the dignity of every human being.

Cultural sensitivity:

We advocate for palliative care to be delivered in a culturally sensitive manner by respecting the values and beliefs of others even when they differ from our own.

Teamwork:

We strive to support one another, working cooperatively, respecting one another's views and making our work environment positive and enjoyable as we work towards achieving our goal.

Welcome



Message from the Chair of the Board

Dear APCA members

APCA continues to play the strategic lead role in harnessing resources, knowledge and expertise to champion the cause of palliative care in Africa.

In the lead-up to and after APCA's last General Assembly, held in Johannesburg in September 2013, where APCA facilitated the passing of a statement by health ministers in Africa on the need to focus more attention on palliative care and to integrate it into health systems, APCA has continued to work towards these tenets both regionally and globally.

In 2013/14 APCA facilitated activities across the continent, with several palliative care programmes supported in 23 African countries. APCA's work continues to revolve around the four strategic objectives for palliative care, namely: awareness creation, integration into health systems, creation of research evidence, and ensuring sustainability.

APCA remains a global voice for palliative care in Africa. During the discussion of the WHA palliative care resolution by the executive board of the WHA in February 2014, our Executive Director on behalf of the Worldwide Hospice and Palliative Care Alliance (WHPCA) made clear his outlook on the topic. The resolution was eventually passed by the full assembly in May 2014.

Despite this success, this year has not been without its challenges, particularly in the face of global economic difficulties. Global funding challenges have resulted in APCA undertaking an internal reorganisation and strategic positioning, which together make the significant achievements highlighted in this report even more impressive.



Dr Bernard Tei Dornoo, Board Chair, APCA

I would like to take this opportunity to thank our donors and partners, our hardworking staff, members of the association, and the members of the board for their continuous collaboration, commitment and dedication to the cause of humanity which made all these achievements possible.

With much gratitude, I look forward to a bright future for APCA and for palliative care in Africa.



Message from the Executive Director

The early visionaries for the establishment of APCA saw the need in Africa, as well as the opportunity, to work towards universal access to palliative care on the whole continent. The year 2013–14 has seen several achievements by APCA that move us closer than ever to meeting the aspirations of those early visionaries.

There are many highlights from this past year for APCA and palliative care in Africa. A few of these include APCA's participation in the technical meetings of the African Union in April 2013, the co-hosting of African health ministers in Johannesburg in September 2013 and the accompanying ministers' statement, and of course our participation in the discussions on the palliative care resolution at the executive board of the WHA in 2014.

This last year has also seen APCA support several programmes and initiatives in 23 countries across the African continent through sub-grants, direct support to some programmes and supporting 'south-to-south' efforts (where Africans are supported to learn from each other as they also learn from our partners from outside the continent).

There is good progress in palliative care policy formulation on the continent and in human resource development for palliative care, as well as in efforts to increase access to palliative care medicines and better service delivery. Efforts in palliative care research are also under way and the African Palliative Care Research Network (APCRN) is growing every day; several significant commentaries and reports relating to palliative care have been published during the year. APCA would also like to take this opportunity to acknowledge the role that survivors of cancer and HIV have played in palliative care awareness efforts.



Dr Emmanuel Luyirika, Executive Director, APCA

All these achievements would not have been possible without the palliative care promoters and funders, as well as governments in Africa and the rest of the world, who have partnered with APCA.

As we enter the new APCA financial year, efforts must be made to ensure that palliative care continues to be seen as a human right for all in Africa and that we all reach out to the most vulnerable bearing in mind the HIV/AIDS burden, the poor infrastructure for cancer care, the rudimentary services available for palliative care for older persons, and the plight of key populations that are at risk of marginalisation.

As the Executive Director of APCA, I am proud of the joint achievements that APCA has made and I am passionate to lead the organisation forward in tackling the challenges ahead.

Introduction



Welcome to the 2013–14 annual report for the African Palliative Care Association. In this report you will find an overview of how we have worked towards our four strategic objectives, which cut across the following key areas: awareness creation; integration of palliative care in health systems; developing the evidence base for palliative care; and sustainability.

This year’s report highlights the very successful palliative care conference, co-hosted by APCA and the Hospice Palliative Care Association of South Africa (HPCA), that was held in Johannesburg, South Africa, in September 2013. It also shares the strides that have been made in national palliative care policies and strategies, as well as in regional developments undertaken by the African Union Commission on palliative care and pain management, among others.

All of this work ultimately aims to move Africa closer to APCA’s core 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” .

Please be assured that APCA’s commitment, energy and drive to realise this mission and objectives is as strong as ever.

How we work

At the centre of all the activities undertaken by APCA are patients, their families and carers. APCA strives to adapt palliative care to African traditions, beliefs, cultures and settings, all of which vary between and within communities and countries on the continent. As such, APCA works with its partners and members to provide African solutions to African problems, articulating them with what is the recognised voice for palliative care across the continent, as it seeks to drive forward its development for all in need.

The role of APCA is not to provide direct clinical care to people living with progressive life-threatening illnesses, but instead to play a facilitative role, working collaboratively with existing and potential providers of palliative and other health care services to expand service provision by building capacity and strengthening health systems by supporting the integration of palliative care at all levels.

APCA works to build effective linkages between all our key stakeholders, including: patients, their families and communities; carers (both family and volunteers); health care providers and educators; African governments, policymakers and decision makers; APCA's constituent members (both individuals and organisations); national palliative care associations, hospices and palliative care organisations; academic institutions; the media; governmental and non-governmental donors (both within and outside the continent); and the general public. These linkages come about, and are strengthened, through a network of national, regional and international partnerships.

APCA's work cuts across four strategic objectives:

- 1 To develop and implement an information strategy on palliative care for all levels of stakeholders in Africa.
- 2 To provide leadership and coordination for palliative care integration into health policies, education programmes and health services in Africa.
- 3 To develop an evidence base for palliative care in Africa.
- 4 To develop and implement a financial sustainability framework for APCA.

What APCA has succeeded in achieving in each of the first three of these strategic objectives during 2013–14 is given next.

Raising Awareness of Palliative Care



APCA is determined to ensure that everyone understands palliative care and its role in the wider health care system. APCA is committed to support policymakers, legislators, academics and students, health care providers, researchers, educators and members of the general public in understanding what good palliative care service provision means to the quality of life of patients and their families. Through our digital Resource Centre, we publish resources designed to support and empower different stakeholders to understand palliative care and the role they can play in changing the lives of both adult and child patients.

During 2013–14, APCA has continued to ensure that palliative care is understood by more policymakers than ever before, including: ministers of health; health care providers; patients and their families; civil society organisations; advocates at the global, regional and national levels; health educators; members of the media; and the legal fraternity.

APCA has helped deliver palliative care in 23 African countries, where people have benefited from palliative care sensitisation and awareness activities during the period under review.

We have also reviewed and refined APCA's online presence by streamlining APCA's website, ensuring that the information and materials on the site are easier to access and easier to use. APCA's website is now acting as the 'hub' of all other online communications with APCA's social media that link both into and out of the new-look website. This approach supports APCA's growing online social media presence, which has continued to grow in size and influence over the last year and has attracted hundreds of new online partners.

These developments are also aiding APCA's efforts to reach out to the media houses, which has resulted in a large growth in mentions within mainstream print and broadcast media both within and outside Africa. Highlights from 2013-14 include:

- Being featured on a prime-time Al-Jazeera report.
- Being mentioned in national and regional print media, including *All Africa* and Uganda's *Daily Monitor*.
- Having articles published in specialist online publications such as *Left Foot Forward* and *The South African*.
- Reaching out to francophone media, including *Le Matin*, *Luxe Radio* and *Libération*.

In addition, APCA still provides the growing Africa edition of the global palliative care news site at www.ehospace.com. This reaches out to a global palliative care community as well as the wider health journalist community.



One of APCA's key awareness-raising projects this year was its response to the "United Nations Political Declaration on Non-Communicable Diseases [NCDs]", the "Global Action Plan on Non-Communicable Diseases" and the "Monitoring and Evaluation Framework on Non-Communicable Diseases" for 2011 and 2012 respectively. APCA organised an Eastern Africa regional consultation meeting on the integration of palliative care in the response to NCDs in April 2013. The meeting, which was attended by 23 participants from three countries, namely **Kenya, Tanzania** and **Ethiopia**, was hosted in collaboration with the **Uganda** Ministry of Health and the Palliative Care Association of Uganda (PCAU).

As a result of the meeting, the four countries have included palliative care in their national policies and

guidelines on NCDs. The countries proposed a set of indicators which included morphine consumption per head of population.

Also in April 2013, APCA, jointly with the Uganda Ministry of Health and PCAU, launched palliative care legal and human rights guidelines and IEC materials in **Uganda**, which are being used to integrate legal support into palliative care services. The materials include: *Human-rights, Ethical and Legal Issues in Palliative Care – A guide for patients and their families*; *Human-rights, Ethical and Legal Issues in Palliative Care – A guide for health care providers* and corresponding posters for health care professionals, patients and families. These were officially launched by Dr Isaac Ezati, the Director of Health Services for Planning and Development in the Ministry of Health in Uganda. The materials for patients



and their families were also translated into one of the largest spoken local languages, Luganda, and plans are under way to translate them into another four local languages which cover the different regions of Uganda.

In April 2013, APCA's Programmes Director represented APCA and the Worldwide Hospice and Palliative Care Alliance (WHPCA) at the World Health Organization's high-level meeting on "Building systems to address functional decline and dependence in ageing populations", in The Hague, Netherlands. As a result of the participation of APCA, WHPCA and other palliative care stakeholders, palliative care was included in the deliberations as well as the outcome document, and it continues to be highlighted in the global and regional health agenda for ageing populations.

In **Uganda**, in collaboration with PCAU and the Ministry of Health, APCA ran a series of workshops for journalists and editors to raise the profile of palliative care as a human rights issue. In addition, APCA conducted three media workshops to raise awareness among journalists on how to effectively report on palliative care. At these workshops, 15 media houses were represented by 42 journalists, who included health reporters and editors. The workshops took place in December 2013, February 2014 and April 2014.

As a result, between February and May 2014, three palliative care stories were covered in two newspapers, two stories in the largest independent national paper (the Daily Monitor) on different dates, and another story in a regional paper, The East African. In April 2014, the Uganda Broadcasting Corporation (UBC) provided free airtime on its health programme to cover palliative care with the aim of increasing public awareness, especially on where and how to access palliative care services.

As part of media support to reporting on palliative care, one health reporter, Zahra Namuli Sentongo, from the Nile Broadcasting Station (NBS) in Uganda was selected and supported to attend the 4th Regional African Palliative Care conference in Johannesburg,

South Africa. This provided her with an opportunity of interfacing with palliative care service providers and experts from across the region and further afield. She has in turn supported APCA and PCAU to mobilise other journalists and media houses to attend palliative care sensitisation workshops and to report on this important issue.

In **Namibia**, palliative care materials have been translated into four local languages of Rukwangali, Oshiwambo, Otjiherero and Afrikaans to facilitate effective communication, delivery of palliative care messages and raising awareness among local communities.

As well as strengthening existing awareness-raising work, APCA has also reached out to countries that have not had palliative care interventions before. In March 2014, the first national palliative care sensitisation and awareness workshop was held for 28 national-level stakeholders in Burundi. The workshop aimed to mobilise local support towards the development of palliative care in Burundi by bringing together local stakeholders to share updates on recent developments in palliative care.

The workshop facilitated the establishment of primary contacts for APCA with relevant stakeholders of palliative care in **Burundi**. Stakeholders were drawn from the Ministry of Health in Burundi, public and private health facilities, civil society organisations, the national nurse syndicate and the University of Burundi – Faculty of Medicine, among others.

This initiative in Burundi was just one of many direct outcomes from the 4th Regional African Palliative Care conference in Johannesburg, South Africa, in September 2013.



“APCA represents patients’ interests when meeting the highest level decision makers”



Integrating palliative care into existing health systems



APCA believes that the most effective way to roll out palliative care is to integrate it into existing health systems as this is the

most sustainable way of reaching more patients and their families who are in need of palliative care.

To this end, APCA provides technical assistance in the following areas



POLICY AND STRATEGY DEVELOPMENT, GOVERNANCE AND LEADERSHIP

We provide support for the inclusion of palliative care into national policies and the implementation of national palliative care programmes.



PALLIATIVE CARE EDUCATION AND TRAINING

We provide education training resources and tools to support the implementation of national palliative care education Programmes. We also support specialist training through bursaries.



MEDICINES AVAILABILITY

We provide guidelines and tools for health care providers and advocates, legislation guidance on use of opioids, education and training to ensure practical steps are taken towards ensuring pain relieving medications are made available to patients in need.



SERVICE DELIVERY

APCA provides the technical assistance for the integration of palliative care in existing health services including public health facilities and NGO health facilities. This is undertaken through capacity building of health care providers and quality improvement interventions.

During 2013–14, APCA has supported palliative care integration into national health policies, guidelines and implementation plans, pre-service and in-service health education and teaching programmes, national medicines

policies, guidelines and regulations, and management systems, as well as in health services in public facilities and NGOs in a total of 23 African countries. Further details on what has been achieved are given next.



Policy and strategy development, governance and leadership

APCA has supported the integration of palliative care into existing health policies, guidelines and strategies, as well as the development of stand-alone palliative care policies and strategies in five African countries, namely **Botswana, Malawi, Tanzania, Uganda** and **Zimbabwe**.

In **Botswana**, APCA, with funding from CDC in Botswana, supported the Ministry of Health of Botswana to develop national pain management guidelines which were adapted from the APCA's *Beating Pain: A Pocket Guide of Pain Management in Africa* (2nd Edition, 2012) and *Guidelines for Ensuring Patient Access to,*

and Safe Management of, Controlled Medicines (2010).

This followed a palliative care experiential visit to Uganda by senior officials from the Ministry of Health and the medicines regulatory body in Botswana to share lessons on the safe use of opioids, and the training of doctors and other clinicians in pain management.

In November 2013, a national palliative care strategy was developed for Botswana, and APCA supported the establishment of the Botswana Hospice and Palliative Care Association, will be launched in July 2014.



In **Malawi**, a national palliative care policy was developed and approved by cabinet in September 2013. It will be launched and disseminated in the next financial year. Palliative care has also been integrated in other local policies and guidelines including: *HIV, Community Home Based Care Guidelines; Standard Treatment Guidelines; and NCD and ART Guidelines*. This has been possible through support from APCA working collaboratively with the Palliative Care Association of Malawi (PACAM) and the Ministry of Health of Malawi.

In **Tanzania**, the “National Palliative Care Policy Guideline” was endorsed by the Ministry of Health and Social Welfare following a policy development process supported by APCA through the Palliative Care Association of Tanzania. The policy guideline is expected to be formally inaugurated in September, 2014.

In **Uganda**, the final draft of a national palliative care policy has been developed and is undergoing the approval processes of the Ministry of Health before presentation to the cabinet and parliament for final ratification. APCA

has worked in partnership with the MoH in Uganda and PCAU on this policy development process. In addition, APCA and its stakeholders in Uganda supported the integration of palliative care in the national policy on NCDs and related frameworks, which were drafted during 2013.

In **Zimbabwe**, the palliative care policy development process was completed and a final policy draft awaits cabinet endorsement. In June 2013, APCA joined the Hospice and Palliative Care Association of Zimbabwe (HOSPAZ) on an advocacy and follow-up meeting with five Ministry of Health and Child Welfare officials, including meeting the Permanent Secretary, Brigadier General (Dr) Gerald Gwinji in order to help facilitate approval of a national palliative care policy and other national frameworks.

APCA has continued to support the implementation of national palliative care policies in **Mozambique, Rwanda and Swaziland** through its various projects and in collaboration with its partners.



Education and training

APCA has supported the training of 780 health professionals in palliative care as well as community-based care providers and volunteers across 14 countries. This was through introductory as well as more specialist training for pre-service and in-service programmes for health professionals. Of those trained, 28 health professionals were supported to either enrol or complete diploma and degree courses in palliative care.

In **Botswana**, 157 health care professionals were trained in palliative care, including 103 students who were trained through four programmes (Family Nurse Practitioners, General Nursing, Dental Therapy and Pharmacy Technology) that have integrated palliative care as an examinable subject at the Institute of Health Sciences in Gaborone.

Others trained include 25 lecturers from seven institutes of health sciences in **Botswana** and seven health care workers from palliative care clinical placement sites in the country. Twenty pharmacists and doctors also received training on pain management, with a focus on safe use of opioids through a collaboration with the MoH. Of those trained, one lecturer from the Institute of Health Sciences in Gaborone and one health professional from Ramotswa Hospice were supported to attend diploma courses at Hospice Africa Uganda's Institute of Palliative Medicine in Africa/Makerere University in **Uganda**.

In the **Democratic Republic of Congo (DRC)** APCA supported seven health professionals, including doctors and nurses from the Ministry of Health and public facilities, to undertake in-depth training in palliative care through a five-week international palliative care initiators course organised by Hospice Africa Uganda to initiate palliative care services in francophone sub-Saharan Africa.

In **Ethiopia**, 17 health care professionals from nine hospitals were supported to undergo APCA's palliative care introductory course.

In **The Gambia**, one senior staff nurse from Serekunda General Hospital completed the Higher Education Diploma in palliative care from Nairobi Hospice in Kenya with support from APCA.

In **Kenya**, 92 health professionals were supported to attend the introductory, training of trainers (TOT), research and diploma courses this year. Of those trained, eight nurses enrolled for palliative care diploma courses in **Uganda** and **Kenya**, while one doctor working with the Kenya Hospices and Palliative Care Association (KEHPCA) enrolled on a Masters course in the UK.

In addition, two social workers – one from Kisumu Hospice in western Kenya and the other from Nairobi Hospice – completed diploma courses in palliative care through Nairobi Hospice/Oxford Brookes University in the UK. APCA also supported the Kenya Hospices and Palliative Care Association to print copies of *Handbook on Legal Aspects in Palliative Care*, which aims to facilitate the integration of legal support in palliative care services.

In **Malawi**, two nurses – one working with Kamuzu Central Hospital and another with Ndimoyo Palliative Care Centre – completed a diploma in higher education in palliative care at the Nairobi Hospice and Hospice Africa Uganda respectively. After completing the diploma in higher education in palliative care, Samuel Truwa from Kamuzu Hospital commented:



“ I am now ready and confident to put into practice the knowledge and skills I have acquired throughout the course for the benefit of patients and their families, the institution and my country. I will take a leading role in promoting provision of quality palliative care to patients in the community and promote team work. I will continue to take part in capacity building of colleagues and community volunteers to promote accessibility of quality palliative care. ”

In **Mozambique**, 30 health professionals, including nurses and doctors, were trained in palliative care through an introductory course using the MoH-approved curriculum developed during the previous year.

In **Namibia** refresher training was given to volunteers of Catholic AIDS Action, and one nurse completed and graduated with a diploma in palliative care with Hospice Africa Uganda/Makerere University. The final draft of a national palliative care curriculum was completed and approved by the Ministry of Health and Social Services. The Social Work Section of the University of Namibia was supported to integrate palliative care into its programmes, and a training handbook was developed.

In **Nigeria**, two professionals were supported to undertake diploma training in palliative care. Of these, one social worker from Ilorin Teaching Hospital completed a five-week initiators' course and a clinical placement at Hospice Africa Uganda. In addition, one nurse from the University College Hospital, Ibadan, enrolled on a diploma in higher education in palliative care at Hospice Africa Uganda.

In **Rwanda**, 101 health care professionals underwent palliative care training through the introductory, TOT, paediatric and research courses in collaboration with the Palliative Care Association of Rwanda (PCAR) and the MoH. Benefiting institutions included Kigali University Teaching Hospital, Kibagabaga District Hospital and Rwamagana District Hospital.

In **Swaziland**, three health professionals were supported to undertake diploma-level training in palliative care. They comprised one doctor from Swaziland Hospice at Home, who completed a postgraduate palliative care programme in Cape Town, South Africa, and two nurses (one from Good Shepherd Hospital and the other from the Swaziland Ministry of Health), who were supported to undertake diploma training in palliative care in Uganda.

In **Tanzania**, a national palliative care training manual for health professionals was developed during the year.

In **Uganda**, 147 professionals, including 98 health care workers and 49 district-based legal practitioners and paralegals, were trained in palliative care through introductory, TOT and paediatric courses, as well as through diploma- and degree-level training in collaboration with PCAU and the Uganda Network on Law, Ethics and HIV/AIDS (UGANET). Of the health care workers, six nurses enrolled and others completed diploma courses at Hospice Africa Uganda/Makerere University and at Mildmay Uganda (paediatric diploma),



and one orthopaedic officer enrolled for a degree course. Twenty of the trained health care workers were also supported to undertake clinical placement in established palliative care centres.

In addition, 59 community volunteers/village health committee workers were trained in palliative care. Ten districts benefited from the training of legal practitioners and paralegals, aimed at facilitating the integration of legal support in palliative care services. Twenty three of the trained paralegals completed clinical placements in various palliative care service centres. Below is the view of one of the trained legal officers after training:

“The training has made me to understand that some patients don’t only need medical care but have several problems including legal problems which need attention. I was able to see physically a palliative care patient at the hospital and it made me realize the suffering [of] the patient’s experience.”

In **Zambia**, 95 health care professionals were trained in palliative care through introductory, TOT and diploma courses in collaboration with the Palliative Care Alliance of Zambia (PCAZ). Benefiting institutions included the University Teaching Hospital, Ndola Central Hospital, Choma General Hospital and Livingstone General Hospital. Those trained included three doctors and one physiotherapist who enrolled on a diploma course with Hospice Africa Uganda/ Makerere University.

In **Zimbabwe**, APCA collaborated with Island Hospice Services to train in palliative care 67 health care providers selected from special needs populations; they underwent introductory and TOT courses. Those trained included 26 LGBT persons, 14 members of the prison service and 27 clergy selected from the United Methodist Church, United Baptist Church and Zimbabwe Assemblies of God in Africa. The important links made with the clergy have created a positive impact on networking and the referral system.

A national palliative care curriculum for health professionals was also drafted during 2014 for Zimbabwe in collaboration with HOSPAZ, and it awaits final approval by the Ministry of Health and Child Welfare.

During 2013–14, two major education and training resources were completed by APCA. These were *Monitoring and Evaluating Palliative Care Education: A framework for palliative care educators and trainers in Africa* and *A Guide to Effective Methods of Teaching Palliative Care: A guide for educators and trainers in Africa*.



Medicines availability

During the period under review 12 countries were supported to improve access to pain medications, especially opioids. APCA interventions ranged from technical assistance for governments in their importation of opioids to the capacity building of health professionals in relation to their effective use and their continued advocacy role.

In **Botswana**, 40 doctors and pharmacists were trained in pain management, with an emphasis on opioid use. The training was organised by the MoH of Botswana with technical support from APCA and co-sponsorship from CDC. Those trained have contributed to the development of national pain management guidelines in the country – an initiative spearheaded by the MoH of Botswana, with funding support from CDC and with technical assistance from APCA during the period under review.

In **Malawi**, a task force of 15 stakeholders was identified and trained on the safe use of opioids, and they thereafter engaged in discussions on the situation of morphine use in the country, including the procurement of morphine powder. As a result the Government of Malawi is purchasing powdered morphine for the whole country, and the Central Medical Stores is undertaking reconstitution of the powder into oral liquid morphine for use by those who need it via accredited health facilities. Moreover, 38 pharmacists were oriented during 2013–14 on the importance and use of morphine in an effort to improve access to pain management in the country.

In **Tanzania**, the MoH approved the inclusion of morphine in the national essential drug list in order to make it more available to the health facilities that have the direct role of using it to manage pain and suffering among palliative care patients. This resulted from an advocacy meeting in November 2013 between the Tanzania Palliative Care Association (TPCA) and the Ministry of Health and Social Welfare, the Tanzania Food and Drugs

Authority and the Drug Controller Officer, Medical Store Department.

In **Rwanda**, APCA supported a meeting of local stakeholders where the supply chain mechanism/ framework for opioids was defined. This meeting was led by MoH Rwanda and the Palliative Care Association of Rwanda, with technical input and support from APCA, the Uganda MoH and the Makerere Palliative Care Unit in Uganda. In addition, two pharmacists from the MoH in Rwanda were supported to undertake an experiential study visit in Uganda, from where they derived lessons for the reconstitution of powdered morphine into oral liquid morphine – to be used at all levels of the health care system in Rwanda, including community level. As a result of these interventions, the Government of Rwanda agreed to procure and reconstitute powdered morphine.

APCA also initiated a study on the supply chain mechanisms, estimating procedures and consumption of opioids in four southern African countries: **Namibia, Swaziland, Mozambique and Zimbabwe**. In Swaziland, data collection was completed and a draft report is available.

In February 2014, APCA entered into a partnership with the Pain Policy Studies Group of the University of Wisconsin in the United States to pilot the first African Pain Policy Fellowship (APPF) programme, aimed at empowering health care practitioners from low- and middle-income countries with knowledge and skills to improve patient access to opioid analgesics for cancer pain management in their countries. Five fellows selected from five countries (Ethiopia, Ghana, Rwanda, Sudan and Zambia) have been enrolled and are being trained through the programme so that they become lead advocates and champions for ensuring access to opioids in their work settings and countries.



Service delivery

During the year, APCA supported the integration of palliative care in more than 58 health facilities/institutions across 14 countries, covering public health facilities, health teaching institutions and NGO health facilities. Of those 58, three facilities received support to ensure ongoing quality improvement and, indeed, developed into palliative care centres of excellence. The three were Livingstone General Hospital in **Zambia**, Swaziland Hospice at Home, and Island Hospice Services in **Zimbabwe**.

In addition APCA supported another four palliative care sites (namely Selian Hospice in Tanzania, Ndimoyo Health Centre in Malawi, Princess Marina Hospital Oncology Centre in Botswana and Moi Teaching and Referral Hospital in Kenya) to undertake a standards audit of their services – from which they developed quality improvement plans. Some of these plans are being implemented in the facilities in order to improve both the provision of palliative care services at the facility and home-based care levels. APCA, with support from the True Colours Trust, also awarded small grants during 2013–14 to 14 organisations/institutions across 11 African countries so as to contribute to greater access to palliative care services, including medicines and equipment for adults and children with life-limiting illnesses. More than 1,500 patients have received palliative care services as a result of such grants.

Benefiting organisations/institutions are outlined in the table below.

Organisation/institution benefiting from APCA small grant	Country
Embu-Mbeere	Kenya
Living Room International	
Meru Hospice	
Fantasum Foundation	Nigeria
Integrated Development Foundation	Cameroon
Kamuzu Central Hospital	Malawi
Tikondane Living Support Organisation	
Naggalama Hospital	Uganda
Shepherds Hospice	Sierra Leone
ACOVIE	Cameroon
Organisation Jeunesse pour le Développement Communautaire, (ORJEDEC),	Togo
Radiation & Isotope Centre, Khartoum (RICK),	Sudan
Hospice Association of Zimbabwe	Zimbabwe
Service Medical Diocese of Aru	Democratic Republic of Congo (DRC)

During the year, APCA also supported the development of linkages between legal and human rights organisations and palliative care providers in Uganda. This has resulted into the integration and provision of legal support to patients and their families as part of palliative care services at Mildmay Uganda. Hospice Africa Uganda has also integrated legal support through linkages with the Uganda Law Society's Legal AID Project.



“Everyone has a right to palliative care”



Building evidence for palliative care in Africa



We are passionate about creating an evidence base for palliative care through academic and field research. Through the African Palliative Care Research Network (APCRN), which strives to conduct research projects and serve as a hub for international research, we strive to ensure that policymaking and palliative care programming is based on sound evidence. We are determined to contribute to the growth of an evidence base of palliative care as a discipline.

Furthermore, research skills development and transfer is key to our work and we aim at supporting research initiatives that improve the lives of patients.

The APCRN has a highly successful mode of partnership that has flourished in Europe via King's College London (Cicely Saunders Institute) and the University of Bonn (Department of Palliative Care), in America (with Measure Evaluation), and in Australia (with HONEXUS). The network also works in very close partnership with PhD students from universities in Africa and Europe.

RESEARCH AND LEARNING

During 2013, the APCRN completed a series of research projects (see below) and has seen a growing evidence base for palliative care in Africa. The network is continuing to engage in cutting-edge research during 2014 and beyond.

THE RESEARCH PROJECTS UNDERTAKEN BY APCA DURING THE PERIOD UNDER REVIEW COMPRISED THE FOLLOWING:

1 Spirituality and palliative care:

During 2013–14 APCA, through the APCRN, conducted a survey on spiritual care within African palliative care services across Africa. The survey sought to understand people's definitions of spirituality, the availability of spiritual care in services, the description of spiritual care services where they exist, gaps in spiritual services where they exist and challenges in providing spiritual care to palliative care patients. The findings will inform a foundation survey of spiritual care provision on the continent.

2 Roles, training and motivations of volunteers in palliative and hospice care:

In collaboration with the European Association for Palliative Care, the APCRN has launched a survey on the roles, training and motivations of volunteers in palliative and hospice care in Africa and Europe. This is one of the success stories for partnering arrangements, because Africa is learning from Europe and vice versa.

3 Palliative care professionals' attitudes to practice and literacy in research:

This survey solicited views of palliative care professionals on whether they thought their current practice to be evidence based, their attitudes towards research, the prevalence (or otherwise) of positive relationships with others, current research



“Without research, palliative care is an art not a science”

practice, research literacy and interest in additional education about research. Findings will inform the development of research training courses for palliative care professionals in Africa and strategies for building the critical mass for palliative care research across the region.

4 Addressing opioid supply-chain constraints in southern Africa:

To advance the agenda of increasing access to palliative care in the region, APCA is supporting efforts aimed at promoting access to opioids for pain management. With support from USAID and in collaboration with local partners, APCA was able to complete a survey on opioid supply-chain constraints in Swaziland, and work in other countries is still under way.

Findings from Swaziland highlighted a need to:

- Increase the categories of health workers who are permitted to prescribe opioids.
- Have in place national palliative care associations to focus on advocating and facilitation of the integration of palliative care at all levels and any other issues pertinent to palliative care.
- Use past consumption records as well as morbidity-based data for estimating opioid need.
- Train health professionals to address issues related to their reluctance to prescribe (which might be caused by myths or lack of adequate knowledge).

THE AFRICAN PALLIATIVE CARE OUTCOME SCALE

At the APCA/HPCA conference held in Johannesburg, South Africa, in September 2013, a research workshop was held for 72 delegates from 16 countries across Africa to obtain feedback from African palliative care practitioners on the use of APCA's African Palliative Care Outcome Scale (African POS).

It was noted that the African POS was one of the most widely used outcome measures and, indeed, was a breakthrough into assessing quality in palliative care: “measuring the quality of care provided was problematic without rigorously validated outcome measures that ... were suitable for use within the resource-constrained and culturally different African context”. (Defilippi and Downing, 2013). APCA continues to provide the African POS free of charge.

Furthermore, APCA and partners are in the final phase of writing up results for a full validation of the Children's POS. The Children's POS takes into account broader domains such as development, play and feeding, and it is underpinned by a systematic review (Journal of Pain and Symptom Management, 2012). This opens up a new opportunity for increasing access to tools to support patient-level research in paediatric palliative care in sub-Saharan Africa. A snap shot of the evidence for validity and reliability will be present at European Association of Palliative Care Congress in 2015.



PUBLISHED RESEARCH

Through active research and collaboration with partners we have been able to demonstrate highlights for African palliative care in journals such as *The Lancet Oncology*, *Journal of Pain and Symptom Management* and *Health and Quality of Life Outcomes*. We are delighted to have contributed to publications that underpin all of our work.

RESEARCH WORK PUBLISHED DURING 2013–14 IN WHICH APCA PLAYED A PART (APCA PERSONNEL SHOWN IN BOLD) IS AS FOLLOWS:

- Harding R, Selman S, **Powell RA**, **Namisango E**, **Downing J**, Merriman A, Ali Z, **Gikaara N**, Gwyther L, Higginson IJ. Research in palliative care in sub-Saharan Africa. *Lancet Oncology*. 2013. 14:183–88.
- Downing J, **Namisango E**, **Kiyange F**, **Luyirika E**, Gwyther L, **Enarson S**, **Kampi J**, Sithole Z, **Kemigisha-Ssali E**, **Masclee M** and **Mukasa I**. The net effect: spanning diseases, crossing borders – highlights from the fourth triennial APCA conference and annual HPCA conference for palliative care. Available online at [ecancer 7 371 / DOI: 10.3332/ecancer.2013.371](http://ecancer.7.371/)
- **Namisango E**, **Powell RA**, Kariuki H, Harding R, **Luyirika E**, Mwangi-Powell F. Palliative Care Research in Eastern Africa. *European Journal of Palliative Care*. 2013.
- Cleary J, **Powell RA**, **Munene G**, Mwangi-Powell FN, **Luyirika E**, **Kiyange F**, Merriman A, Scholten W, Radbruch L, Torode J, Cherny NI. Formulary availability and regulatory barriers to accessibility of opioids for cancer pain in Africa: a report from the Global Opioid Policy Initiative (GOPI). *Annals of Oncology* 24 (2013) xi14-xi23. Also available online at www.ncbi.nlm.nih.gov/pubmed/24285225
- Harding R, Selman L, Ali Z, **Powell RA**, **Namisango E**, Mwangi-Powell F, Gwyther L, **Gikaara N**, Higginson IJ, Siegert RJ. Wellbeing among sub-Saharan African patients with advanced HIV and/or cancer: an international multi-centred study comparing two outcome measures. *Health and Quality of Life Outcomes*. 2014. Also available online at www.hqlo.com/content/12/1/80
- Harding R, **Namisango E**, **Powell RA**, Merriman A, **Gikaara N**, Ali Z, Higginson IJ. Palliative care-related self-report problems among cancer patients in East Africa: a two country study. *Journal of Supportive Care in Cancer*. 2014. Also available online at <http://link.springer.com/article/10.1007%2Fs00520-014-2301-5>
- Siegert R, Selman L, Higginson IJ, Ali Z, **Powell RA**, **Namisango E**, Mwangi-Powell F, Gwyther L, **Gikaara N**, Harding R. A psychometric evaluation of the Functional Assessment of Chronic Illness Therapy – Palliative Care (FACIT-Pal) Scale with palliative care samples in three African countries. *Journal of Pain and Symptom Management*. 2014. Also available online at www.ncbi.nlm.nih.gov/pubmed/24742786
- Downing J, Gomes B, **Gikaara N**, **Munene G**, Daveson BA, **Powell RA**, Mwangi-Powell FN, Higginson IJ, Harding R on behalf of Project PRISMA. Public preferences and priorities for end-of-life care in Kenya: a population-based street survey. *BMC Palliative Care*. 2014. Also available online at www.biomedcentral.com/1472-684X/13/4



- Penfold S, **Namisango E, Banga G, Kataike J, Atieno M, Munene G**, Moreland S, Downing J, Higginson IJ, Harding R, **Gikaara N**, Simms V, Mwangi-Powell F, **Powell RA**. The HIV Basic Care Package: Where is it available and who receives it? Findings from a mixed methods evaluation in Kenya and Uganda. *AIDS Care*. 2014.
Also available online at:
www.ncbi.nlm.nih.gov/pubmed/?term=Penfold+S%2C+Namisango+E%2C+Banga+
- Harding R, Simms V, Penfold S, Downing J, **Powell RA**, Mwangi-Powell F, **Namisango E**, Moreland S, **Gikaara N, Atieno M, Kataike J**, Nsubuga C, **Munene G, Banga G**, Higginson IJ. The presence of CD4 counts for the management of HIV patients in East Africa: a multicentred study. *AIDS Care*. 2014.
Also available online at
www.ncbi.nlm.nih.gov/pubmed/24099416
- **Powell RA**, Harding R, **Namisango E**, Katabira E, Gwyther L, Radbruch L, Murray SA, El-ansary M, Leng M, Ajayi IO, Blanchard C, Kariuki H, Kasirye I, Namukwaya E, Gafer N, Casarett D, **Atieno M**, Mwangi-Powell F. Palliative care research in Africa: Consensus building for a prioritized agenda. (Special Article). *Journal of Pain and Symptom Management*. 2014.
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www.ncbi.nlm.nih.gov/pubmed/23870840
- Siegert R, Selman L, Higginson IJ, Ali Z, **Powell RA, Namisango E**, Mwangi-Powell F, Gwyther L, **Gikaara N**, Harding R. A Psychometric Evaluation of the Functional Assessment of Chronic Illness Therapy – Palliative Care (FACIT-Pal) Scale with palliative care samples in three African countries. *Journal of Pain and Symptom Management*. 2014. doi: S0885-3924(14)00183-3.
Also available online at
www.ncbi.nlm.nih.gov/pubmed/24742786
- Ajayi IO, Iken OF, **Powell RA, Namisango E**, Mwangi-Powell FN. Palliative care research in Africa: Western Africa. *European Journal of Palliative Care*, 2014



Promoting sustainability for palliative care



APCA believes in the value of partnership and collaboration in order to make a difference –bringing together the strengths and resources of multidisciplinary stakeholders to make our collective voice stronger. The areas in which we provide technical assistance for organisational development include (but are not limited to): governance and management; financial and human resource management; strategy development and implementation; programme development and implementation; monitoring and evaluation to ensure quality services for African patients and their caregivers; fundraising; marketing and branding; and website development.

This year, APCA strengthened institutional capacity of more than 58 organisations/institutions. For example, Island Hospice Services in Zimbabwe was supported in the review of its management and governance structures; Hospice Palliative Care Association of Zimbabwe; Tanzania Palliative Care Association and the TONATA Network of People Living with HIV in Namibia were supported to develop their strategic plans. The Palliative Care Association of Rwanda (PCAR); HOSPAZ and Island Hospice Services in Zimbabwe received technical assistance in finance management. In Ethiopia, the process for establishment of a national palliative care association commenced with support from APCA.

SUSTAINABILITY

To ensure consistent service delivery to our partners and colleagues across Africa, we ensure the sustainability of our work. A key part of this is guaranteeing financial sustainability. In a very challenging economic environment, ensuring this sustainability has become a growing priority for APCA.

The various initiatives in this report are meant to result in the achievement of sustainability as evidence-based approaches are used to ensure that palliative care is integrated into national health and education systems. Sustainability of country programmes is enhanced by working with local partners in the different countries who take forward the work beyond project funding.

We strive to generate unrestricted funding through office rentals, sales of publications, interest income as well as fees from membership and technical assistance to partners. This stream of funding is still minimal but APCA plans to offer more paid technical assistance in future to raise more income.



GOVERNANCE

Governance oversight is provided by the APCA board, which is made up of 11 members located in different countries comprising Ghana, Morocco, Namibia, Nigeria, South Africa, Uganda and the United States. During the year under review, we held four board meetings – in June 2013, September 2013, November 2013 and March 2014. APCA also held a general assembly in September 2013, where APCA shared the progress of its work with members. At this meeting, new auditors Deloitte and Touche were appointed.

MONITORING AND EVALUATION

In order to closely monitor progress against its plans, APCA used the Performance Monitoring Plan tool (PMP). At the beginning of the year, key indicators were captured in the system and this was updated with data collected throughout the year from the various projects. The tool has been key to tracking progress against set targets, not only at project level but also for the organisation as a whole.

APCA also provided monitoring and evaluation capacity building sessions for both APCA staff and partners. Follow-up monitoring visits were undertaken for partner organisations in a number of countries including Kenya, Malawi, Namibia, Tanzania, Uganda and Zimbabwe. This has resulted in a better understanding of, and compliance with, monitoring, evaluation and reporting requirements among staff and partners. As a result, there has been an improvement in the quality of data collected during the period under review.

MANAGEMENT SYSTEMS

APCA employs competent qualified staff to implement its programmes. We implement effective internal controls to ensure the safeguarding of organisational resources and the smooth running of operations. We have a good financial management system to ensure quality and the timely generation of financial information for all stakeholders. We also maintain a monitoring and evaluation system that tracks our performance against set targets.

APCA is committed to providing timely narrative and financial reports to its donors in order to ensure grant compliance, thus maintaining good donor relations. We also provide technical support to our partners to improve their systems.

In November 2013, APCA won the Financial Reporting Award for NGOs (health sub-category) given by the Institute of Certified Public Accountants of Uganda.

ICT SYSTEMS

In January 2014, APCA purchased new server equipment with support from the True Colours Trust. APCA also installed new software donated by Microsoft. This improved the organisation's IT functionality and server storage space.

APCA was then able to communicate regularly with its partners through email and Skype. We held several meetings with stakeholders all over the world via Skype which reduced meeting costs. For example, two of the board meetings were held via Skype in order to cut travel costs for the board members who are geographically dispersed.

Report on the APCA/HPCA Conference



CONFERENCE THEME: “THE NET EFFECT: SPANNING DISEASES, CROSSING BORDERS”

With the aim of advancing the vision of APCA to promote and make palliative care accessible for all in Africa, the organisation continues to link national, regional and international players to learn and share lessons. It is for this reason that APCA jointly held its 4th Regional Triennial Palliative Care Conference for Africa with the annual conference of the Hospice Palliative Care Association of South Africa (HPCA) from 17 to 20 September 2013 at Birchwood Hotel, Johannesburg, South Africa. The theme for the conference, “The Net Effect: Spanning Diseases, Crossing Borders”, reflected a joint vision and the drive to remember the ‘net effect’ of our work in palliative care – that is, the ultimate impact of the care that we provide for our patients and their families across the disease and age spectrum and across the borders of African countries. The conference brought together 471 delegates from 34 countries across the world, of which 24 were African countries.

PRE-CONFERENCE SESSIONS

As part of the conference, an inaugural pre-conference ministers-of-health session was held on the 17 September 2013. The session was hosted and chaired by Hon Dr Gwen Malegwale Ramokgopa, Deputy Minister of Health of the Republic of South Africa, and co-chaired by Dr Jonah Wefuan, from Cameroon and Chair of the APCA Board of Directors. This pre-conference session attracted and inspired 92 delegates from 23 countries, including 21 African countries. Of these, 34 delegates represented ministries of health, including four ministers and deputy ministers (from Kenya, Uganda, Malawi and South Africa) and representatives of ministers of health from various countries across Africa.

The African Union Commission was also represented at this session by its Senior Policy Officer of Health, Population and Nutrition. The main outcome from the Ministers of Health session on palliative care was the adoption of a “Consensus statement for palliative care integration into health systems in Africa: Palliative Care for Africa”. The statement builds on the African Union Ministers of Health Declaration on Non-Communicable Diseases, in which African governments committed to the integration of palliative care as well as the African Union common position on the use of pain medications, along with other regional and UN declarations.

Another pre-conference workshop, which focused on the research agenda for palliative care and how to sustain a vibrant research culture in Africa, attracted 156 palliative care and health researchers from Africa, Europe and the United States. They identified ways to collaborate and engage in the palliative care research agenda, and discussed priority research areas, which included: the palliative care needs of children; the impact of palliative care training on care and practice; palliative care integration; outcomes of care; palliative care needs assessment; assessment of drug availability and accessibility; and volunteers in palliative care.



MAIN CONFERENCE SESSIONS

The main conference brought together 471 delegates from 34 countries. Twenty four countries were within Africa, namely Botswana, Burundi, Cameroon, Côte D'Ivoire, Democratic Republic of Congo, Ethiopia, the Gambia, Ghana, Kenya, Malawi, Morocco, Mozambique, Namibia, Nigeria, Rwanda, Sierra Leone, South Africa, Sudan, Swaziland, Tanzania, Togo, Uganda, Zambia and Zimbabwe. The other 10 countries comprised Austria, Canada, England, Italy, Hungary, Germany, Malaysia, Scotland, Sweden and the United States.

The conference brought together clinicians, academicians, human rights advocates, lawyers, clergy, researchers, social workers, policymakers, Ministry of Health officials, donors, members of the press, and national palliative care associations. Delegates had a common aim of sharing lessons learned and adopting or reporting on best practice for strengthening and integrating palliative care. Partner agencies and governments were represented by decision makers and technical experts from within and beyond Africa.

The conference was organised into four tracks: (1) spanning diseases with palliative care; (2) crossing borders with health systems strengthening; (3) showcasing impact; and (4) sustaining our work. The scientific programme included plenary sessions where 11 papers were presented, 64 oral breakout presentations, 16 workshops and 104 poster presentations.

The key themes and messages from the conference can be summarised as: commitment to political will and support at the highest levels of governance; engaging national, regional and international bodies; collaboration; diversity; palliative care for children; planning for human resources and capacity building; palliative care integration at all levels; developing an evidence base for palliative care in Africa; using new technologies; and improved quality of care.

During the conference, lifetime achievement awards were presented to Professor Anne Merriman (Hospice Africa Uganda) and Kath Defilippi (formerly HPCA) for their significant impact in contributing to palliative care development in Africa, and a pioneering leadership award to Dr Faith Mwangi-Powell. In addition, with funding from the Open Society Foundations, public health policy, advocacy and journalistic awards were presented to ministries, institutions and individuals in recognition of their excellence in advancing palliative care in Africa. There were also special awards for commitment to palliative care research, best research abstract and best poster presentation.

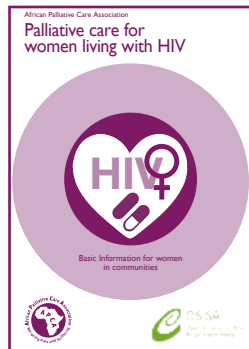
Delegates found a renewed commitment and passion for palliative care and related health interventions for children and adults with life-limiting and life-threatening illnesses within the region. They were also united in the fact that together we can 'span diseases', 'cross borders', and realise the 'African Dream' for palliative care.

APCA Resources



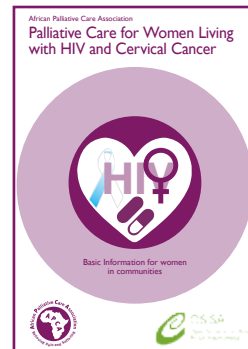
One of the ways in which APCA strives to ensure that palliative care is widely understood, integrated into health systems and underpinned by evidence is through the development of palliative care materials and resources tailored to the needs of African patients and health care providers. These materials cover awareness, policy, advocacy, education and quality improvement in palliative care.

Electronic versions of the following resources can be downloaded free of charge from the Digital Resource Centre on APCA's website, categorised according to publication language and by year of publication. African partners may receive technical assistance from APCA in the adaptation of these resources to their local context.



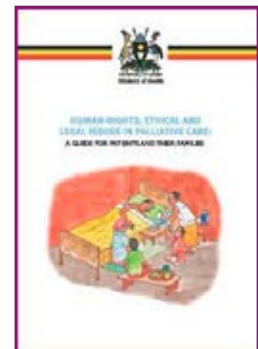
Palliative Care for Women Living with HIV (2013)

The information in this monograph is intended to help women living with HIV and those in the community who support them, such as their families, caregivers and health professionals. The document provides a framework towards understanding the role of palliative care in such circumstances, although individual situations might require more specific information than what is provided in the publication. ***This resource is available in English, French and Portuguese and has been developed in partnership with the Open Society Initiative for Southern Africa***



Palliative Care for Women Living with HIV and Cervical Cancer (2013)

The information in this monograph is intended to help women living with HIV as well as cancer of the cervix, and those in the community who support them such as their families, caregivers and health professionals. The document provides a framework towards understanding the role of palliative care in such circumstances, although individual situations might require more specific information than what is provided in the publication. ***This resource is available in English, French and Portuguese and has been developed in partnership with the Open Society Initiative for Southern Africa.***



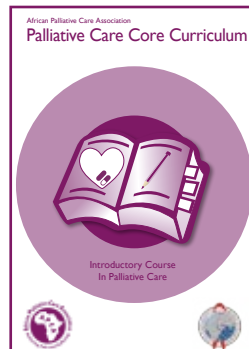
Human rights, ethical and legal issues in palliative care (2013)

This guide, for patients and their families, highlights patients' rights in relation to access, humane and ethical care, and the delivery of palliative care. The guide helps patients in relation to the care received, provides insights into the common legal and human-rights issues they may encounter, and encourages them to share these with their health care provider for support. ***This resource is available in English and Luganda and has been developed in partnership with the Open Society Initiative for Eastern Africa.***



A Framework of Core Competencies for Palliative Care Providers in Africa (2012)

To guide the provision of quality palliative care services across the African region, APCA has developed a framework of core palliative care competencies that can be used by service providers, educators and other stakeholders to guide programme development. These competencies also provide useful guidance when designing and implementing targeted and effective education programmes in palliative care, aimed at producing highly competent care providers. **This resource is available in English and has been developed in partnership with AIDSTAR-One.**



Palliative Care Core Curriculum (2012)

To contribute to the availability of basic knowledge and skills for the provision of palliative care in Africa, APCA has developed a competency-based core curriculum framework for use in introductory training on palliative care. The curriculum incorporates theoretical, practical, mentorship and supervision components that are critical to the effective application of knowledge in practice. **This resource is available in English and has been developed in partnership with AIDSTAR-One.**



APCA Standards for Providing Quality Palliative Care across Africa (2011)

This resource covers the following five principles in palliative care provision: organisational development; holistic care provision; children's palliative care; education and training; and research and management of information. **This resource is available in English and has been developed in partnership with the Elton John AIDS Foundation.**



Guidelines for the Use of the APCA African Palliative Outcome Scale (POS) (2011)

This guide provides a simple tool for measuring care outcomes for patients receiving palliative care and walks you through the steps of using the tool; it also explains how to analyse and use generated data for the improvement of patient care. The development of a children's version of the POS is under way. **This resource is available in English and has been developed in partnership with AIDSTAR-One.**



Successful Advocacy for Palliative Care: A Toolkit (2011)

This guide is directed at champions of palliative care across Africa and is packed with advice for working with policymakers, the media and the public to win support for palliative care provision. It provides useful frameworks for engaging with governments to prioritise palliative care as an approach for health systems strengthening. **This resource is available in English and French and has been developed in partnership with DFID and Help the Hospices.**



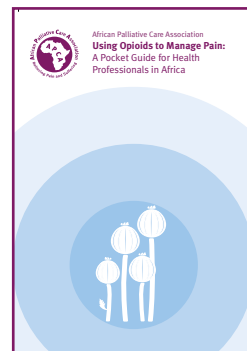
Guidelines for Ensuring Patient Access to, and Safe Management of, Controlled Medicines (2010)

These guidelines cover essential regulatory and administrative measures needed to achieve the appropriate approach to safely managing opioid medicines and their access to patients. They allow policymakers, service providers and drug regulatory bodies to navigate the supply chain for Class A drugs. **This resource is available in English and has been developed in partnership with the True Colours Trust.**



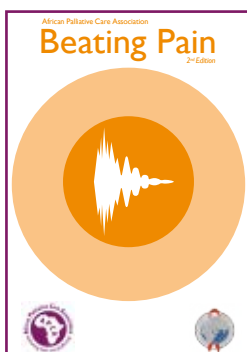
Palliative Care: A Handbook of Palliative Care in Africa (2010)

This resource targets the general population, including busy managers and administrators, to introduce them to palliative care. Compiled as a comprehensive manual, this handbook contains essential information on palliative care provision in the African context and is a useful resource for palliative care service planning. The manual includes a section on children's palliative care. **This resource is available in English, French and Portuguese and has been developed in partnership with AIDSTAR-One.**



Using Opioids to Manage Pain: A Pocket Guide for Health Professionals in Africa (2010)

A succinct guide to opioids for medical practitioners, this pocket guide includes compelling justification for their use (including countering some myths about opioids), as well as advice on pain evaluation and how to use opioids to manage different levels of pain. **This resource is available in English and has been developed in partnership with The True Colours Trust.**



Beating Pain: A Pocket Guide for Pain Management in Africa (2010)

This guide targets clinicians to improve their knowledge and skills in managing pain in an African clinical setting, paying special attention to children's needs. **This resource is available in English, French and Portuguese and has been developed in partnership with AIDSTAR-One.**



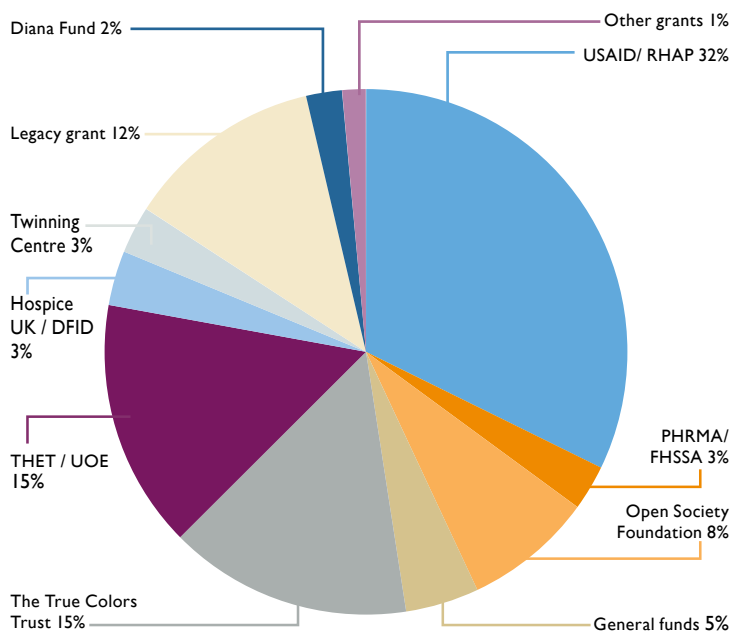
“APCA has supported the training of 780 health professionals in 14 countries to ensure patients are central to their work”



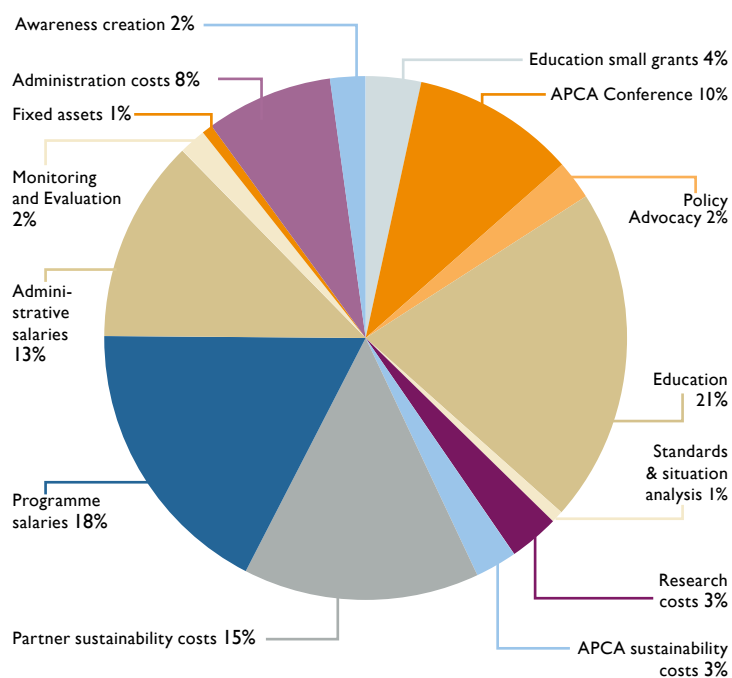
Financial Report



Where the money came from 2013/14



Where the money went 2013/14



Sources of income	Bal b/f 1/4/2013	Restated Income 2013/2014	Total available funds 2013/2014	Percentage of total income 2013/2014
USAID/ RHAP	372 122	856 540	\$1 228 662.00	32%
PHRMA/FHSSA	49 527	56 489	\$106 016.00	3%
Open Society Foundation	95 675	207 650	\$303 325.00	8%
General funds	61 312	111 398	\$172 710.00	5%
The True Colors Trust	231 606	340 194	\$571 800.00	15%
THET /UOE	-40 681	623 741	\$583 060.00	15%
Hospice UK / DFID	10 271	117 939	\$128 210.00	3%
Twinning Centre	33 232	77 985	\$111 217.00	3%
Legacy grant	463 545	-	\$463 545.00	12%
Diana fund	84 761	-	\$84 761.00	2%
Other Grants	45 836	9 896	\$55 732.00	1%
Total	1 407 206.00	2 401 832.00	3 809 038.00	100%

Expenditure area	2013/2014	2013/2014
Small grants	\$87 835	3%
APCA Conference	\$258 064	10%
Policy Advocacy	\$61 500	2%
Education	\$526 630	21%
Standards & situation analysis	\$19 225	1%
Research costs	\$79 040	3%
APCA sustainability costs	\$66 079	3%
Partner sustainability costs	\$374 292	15%
Programme salaries	\$448 059	18%
Administrative salaries	\$320 022	13%
Monitoring and Evaluation	\$42 416	2%
Fixed assets	\$16 922	1%
Administration costs	\$200 557	8%
Awareness creation	\$56 095	2%
Total	\$2 556 736.00	100%

Other grants: include APCA UK, WHO& Live, strong Foundation , Premiere and American Cancer Society

Donor Appreciation

Our work is made possible because of the generous contributions of our donors. APCA is committed to making sure every contribution we receive is spent with patients and their families in mind.

APCA would like to thank every one of our donors for helping us to advocate for the relief of pain and suffering for patients across Africa. In particular, these include:

- American Cancer Society
- American International Health Alliance (Twinning Center)
- Foundation for Hospices in Sub-Saharan Africa (FHSSA)
- Help the Hospices, with funding from DFID (the UK Department for International Development)
- Livestrong Foundation
- National Association of Social Workers (NASW) of the United States.
- Open Society Foundations – New York (OSF)
- Open Society Initiative for Eastern Africa (OSIEA)
- Open Society Initiative for Southern Africa (OSISA)
- President's Emergency Plan for AIDS Relief (PEPFAR)
- The Diana, Princess of Wales Memorial Fund – legacy grant
- The Global Health Academy and University of Edinburgh, with support from DFID
- The True Colours Trust
- USAID Southern Africa (Regional HIV/AIDS Programme)
- USAID Tanzania
- USAID Namibia
- USAID Malawi.

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.

If you would like to support APCA financially, please let us know by emailing donate@africanpalliativecare.org and we will contact you with further details.

Alternatively, please visit our website www.africanpalliative.org and click 'donate'.

Thank you for your support.

African Palliative Care Association

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NGO Registration Number 4231



INTEGRATING PALLIATIVE CARE