GIVING BACK QUALITY OF LIFE

African Palliative Care Association
APCA
Ensuring Quality - Extending Coverage

Annual Report | 2009/10

“We empower the patient to do whatever they can for themselves”

Tears of gratitude roll down Pondayi Machaka’s face when the team from Island Hospice Service (Island) arrive at his home in Chitungwiza, Zimbabwe – but he can’t wipe them away. Once a taxi driver, 37-year-old Pondayi can do little for himself: he has HIV and TB, and was recently paralysed by a stroke. Community volunteer Bibiana Hazani (above, kneeling) gently dries his face. By day, she cares for him constantly, with training and help from Island; at night, his 19-year-old son takes over. “I get good support,” says Bibiana. “If there’s a problem, I phone Island. Gloves, cough drops, painkillers, counselling, they bring whatever’s needed. It’s free and we’re so grateful. They train us so we can care for the patient without infecting ourselves with HIV; in diet and exercise to keep them moving, and to empower the patient to do whatever they can for themselves. I’d like to be a nurse: the caring is so rewarding.”

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THANK YOU TO ISLAND HOSPICE SERVICE, ZIMBABWE

APCA thanks the staff and patients of Island Hospice Service, Zimbabwe who so willingly helped us illustrate aspects of palliative care delivery in this report. The commitment and drive shown by organisations such as Island are vital in helping attain APCA’s goal of palliative care for all in need in Africa.

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WELCOME TO APCA

It’s our pleasure to present APCA’s 2009/10 Annual Report. As with all APCA’s work, it has at its core Africa’s palliative care patients, and their families and carers. They, and the millions of people who need palliative care but are not fortunate enough to receive it, are behind everything we do. We hope the report reflects this, not just in its inspiring case studies but in every action and strategic choice described.

The report’s theme is ‘the difference we all make’ – a reflection of the incalculable benefit brought to people’s lives by anyone involved with or supporting palliative care in Africa. It’s a difference we want to acknowledge and celebrate.

To ensure that this difference is as strong and as focused as possible, we’ve looked hard this year at APCA’s approach, organisational structure and strategy. As the global economy has shrunk and donor budgets tightened, we’ve asked ourselves some tough questions: are we working in the fields where we can have the biggest impact? Are we in the right countries? What should our future strategy look like? And do we have the best organisational structure to navigate forward in the current context? Answering these questions will help us to really make sure we’re fit for the future in this economic climate.

As a result, we’ve made some exciting changes. We launched APCA UK, to increase awareness in Europe of Africa’s need for palliative care and to raise much-needed funds. We closed our South African office, moving our regional base to our existing programme office in Namibia, where it’s closer to our work on the ground. And we’re reviewing our work priorities so we can focus our energies on areas where we can have the highest impact – such as advocacy and providing top-quality information and training materials tailored to Africa’s needs.

Despite the much-needed change, the year has seen many achievements. We completed the APCA Standards for African Palliative Care – the cornerstone of training and assessment of services across the continent. In many countries we continued to drive the availability of morphine, so essential to pain control, and we reached out to new regions, including North Africa. We built capacity in national associations and palliative care providers, helping them monitor and improve the quality of their services, and prepared for our third conference, in September 2010.

APCA is privileged to play a key role in bringing together members of Africa’s palliative care community – to share experience and learning; to give support and guidance, and for mutual encouragement. The need for palliative care may still be overwhelming, but it’s important that we remind each other that we really can help improve the lives of patients and their families.

We offer sincere thanks to everyone working so hard to bring palliative care to Africa, especially all those who support APCA directly: our donors, partners and friends. We hope we can continue to rely on your generous support in the years ahead, as we further streamline our approach. Please be assured of the tremendous difference you make to people with life-threatening illnesses across Africa.

Dr Faith Mwangi-Powell
Executive Director

Professor Mark Jacobson
Chair, Board of Directors

APCA'S AIMS

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.

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.

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. Our key areas of work include:

- *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 to train others to use them.

- *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 the World Health Organization (WHO) as essential for effective pain control are not legally available for medical use). We also support national palliative care organisations in their advocacy, both directly and through tailor-made resources.

- *Monitoring and evaluation, and research*
  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.

- *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 that of drug availability. We can't ignore the fact that excellent medications exist for the control of physical pain and 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 morphine – are available to everyone. Alongside our local partners, APCA is advocating with governments in countries such as Namibia, Zambia and Kenya to change attitudes to opioids and promote policies and delivery mechanisms that enable proper access to morphine.

Freeing people from unnecessary pain

We try to create as many opportunities to boost palliative care as we possibly can. For example, at the conference of Pharmaceutical Research and Manufacturers of America (PhRMA) in March 2010, we addressed the CEOs of more than 200 leading US pharmaceutical companies, and asked whether they could help us ensure that the life-changing medications they develop reach those in need. The response was overwhelmingly positive: 'Just tell us how!' Now they're contributing generously to training African doctors in palliative care and pain control, to develop their skills in assessing pain and prescribing morphine.

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 health care 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.

"I want to be part of life"

Curled up with pain when Nurse Mary Mtisi from Island Hospice arrives at her home near Harare, 26-year-old Privilege Mandeya gradually relaxes as the painkillers Mary gives her take effect. Privilege has cervical cancer and HIV. "Mary's like a mother to me," she says. "I'm very free with her, I have nothing to hide. She brings me pills to stop my pain and gives me counselling. I was so weak before, now I can walk and bathe again on my own. I don't want to be like that: I want to be outside, talking, seeing people, being part of life. I don't want to be shut inside during the day. I wasn't surprised when I got HIV from my husband. We have three children, aged nine, six and one. It's very hard for me, but with my mother, I know I'm not alone."

When it comes to having her photo taken, Privilege even laughs: "I haven't combed my hair for two weeks!" In just half an hour, palliative care has transformed her.

EDUCATION AND STANDARDS

It's APCA's aim that no doctor, nurse or health professional in Africa qualify without good knowledge of palliative care. Our education and training programme aims to bring this knowledge to all service providers and educators – whether formal health workers or community-based care givers. We regard education and training as a continuum at all levels of service delivery, from primary to specialist, from undergraduate level through to continuing education – critical for ensuring the appropriate knowledge, skills and approach in everyone who delivers palliative care.

A key step towards this was the completion of APCA's **Standards for Providing Quality Palliative Care Across Africa**, specifically tailored to the continent's needs to ensure palliative care is of high quality and appropriate to its setting. The Standards cover all aspects of holistic palliative care, at three levels of service delivery: primary, providing the minimum package for palliative care; intermediary, providing a wide range of care, and specialist, providing the full range.

The Standards will provide training targets and act as a benchmark for monitoring services. They will be distributed at both policy and service delivery levels, alongside guidelines for their adaptation into country or organisational context (APCA will help users to adapt them and we're developing tools so services can audit themselves and develop quality improvement plans). The Standards will be supported by the publication later in 2010 of core **Competencies** for palliative care practitioners, developed in collaboration with international and regional experts through a comprehensive review of existing worldwide competencies and building on them to meet Africa's needs. Both the standards and competencies are informing the development of a core curriculum for introductory palliative care training in Africa for professional and non-professional care providers, which will be available later in 2010.

Further new resources include two guides, **Beating Pain: A Pocket Guide for Pain Management in Africa** and **A Handbook of Palliative Care in Africa**. These are the result of a consultative process involving experts from across Africa, who agreed the outline content and format of the books, then wrote chapters according to their specialities, before independent review. The books will be portable, yet comprehensive enough to contain all essential information on pain management and holistic palliative care in the African context. Both pay special attention to children's needs. APCA is also pioneering electronic education in Africa by developing self-directed learning through a CD which will accompany the Beating Pain Pocket Guide.

As a first step in developing a core curriculum for Africa, APCA **reviewed palliative care curricula and training materials** across the continent. Eight curricula were graded according to their alignment with APCA's Standards and Competencies. The strongest parts from each will be brought together to form the basis of an Africa-specific curriculum, which APCA will distribute to organisations, ministries of health and teaching institutions for adaptation to their local context. Training materials are also being developed and we will support institutions in adapting both for their use.

APCA continued to **build capacity in nursing and medical teaching institutions**, in particular in Botswana, through our partnership with the Institute of Health Sciences, Gabarone, and seven sister institutes across the country. We arranged study visits to Uganda and South Africa for lecturers; provided palliative care training and awareness-raising; reviewed work plans and supplied basic reference materials. The programme now includes the University of Botswana and all teaching institutions in Malawi and Kenya.

In partnership with the Infectious Diseases Institute in Kampala, APCA helped **introduce palliative care into two rural districts in Uganda**. Alongside colleagues from the Palliative Care Association of Uganda and Hospice Africa Uganda, we trained health care professionals and community volunteers, provided follow-up and mentoring, and introduced pain medication.

A **review of home-based care delivery models** for people living with HIV and AIDS was finalised and used to develop APCA's Standards, as well as practical recommendations on integrating palliative care into home-based care services. After a literature review covering Africa and bey=ond, we carried out field research in Kenya, Malawi, Tanzania and Zambia. The draft report was sent to research sites and health ministries for input before being finalised and distributed.

APCA hosted a two-day World Health Organization meeting in Kampala to obtain a regional position on the Organisation's **decent care values** in palliative care services. More than 50 people from 10 African countries – including patients living with HIV and AIDS and/or cancer, service providers, policy makers and donors – discussed how well decent care values are applied in African palliative care, noting that decent care values are already embodied in palliative care's ethos. However, testimonials from several patients showed that practice in palliative care often doesn't mirror theory, so delegates recommended strategies to strengthen the values, such as training for health workers; empowering patients to push for their rights; sharing practice, and influencing policy-makers.

> "It's always people's first fear: What will happen to my children when I've gone?"

'As social workers, we work as a team with the nurses: they give medication and injections, so people feel better; our injections are words. People also feel much better after talking about their feelings. We don't force them, we encourage them: I want to see them wearing a smile. Our patients' number one fear is always about their children: "What's going to happen to them when I die? I wish I had another few years so I could see my children grow." We offer patient and family support, and bereavement counselling, individually and in groups, encouraging members to support each other. We design specific programmes for children, who are often excluded from discussion around illness and dying. We want to introduce reality, and help prepare them for a death in the family, as well as cope with it afterwards. If parents with HIV tell their children, it helps them both: the children want to help their parents live positively.'

Elgar Dhliwayo, Senior Social Worker, Island Hospice Service, Zimbabwe

MENTORSHIP

Through mentoring and collaborative work with national associations, palliative care champions and service providers across Africa, APCA builds capacity and helps partners to provide more and better quality palliative care. In turn, they change the lives of increasing numbers of people who so badly need relief from physical and psychological pain. By developing and nurturing strategic partnerships with donors, supporters and palliative care experts both in Africa and internationally, APCA has continued to ensure the sustainable growth of palliative care across the continent.

Networking and support: national palliative care associations

Central to APCA's mentoring role are Africa's national palliative care associations. We work with each according to its individual circumstances, providing the necessary support and helping it develop. We also help associations connect with one another, so they can develop a strong network of mutual support.

To strengthen that network and clarify their relationship with APCA, we held two meetings bringing together representatives of palliative care associations from nine African countries. At the first, each association shared its current position and context, so we could see how they relate to one another, what each is doing and how we can all support each other. Participants also reached consensus on the role they'd like APCA to play: actively helping develop new associations, and providing assistance to mature ones as needed. They also identified particular areas in which they'd like more support from APCA.

As a result, at the second meeting, we worked with participants to start developing tools and guidelines, such as finance manuals and policies for good governance, to help national associations develop strong organisational structures and operating procedures. We also ran a day-long workshop to help associations meet the challenge of sustainable resourcing, addressing questions such as writing successful funding proposals; identifying an association's main selling points to potential donors; budgeting, and planning project implementation and monitoring.

We continue to support the associations as they put their learning into practice in a wide range of country contexts. In Malawi, for example, when the government proved resistant to procuring the ingredients for oral morphine, APCA helped the Palliative Care Association of Malawi (PACAM) train the media in advocating for proper pain management. As a result, journalists were proactive in pressing for palliative care and morphine availability. A front-page article in *The Nation* newspaper ignited the debate, describing the agony of a patient with oesophageal cancer who died without pain relief while his carers looked on helplessly. The subsequent outcry caused the Ministry of Health to work with PACAM and procure 5kg of morphine powder to distribute to hospitals. As a result, PACAM received two awards from USAID, for innovation and problem solving.

Building partnerships for change

APCA works with partners and governments in countries where we can make the biggest difference, and we tailor our support according to the circumstances in each individual country.

Alongside Hope Worldwide, we carried out a review of palliative care documents developed under **Cote d'Ivoire's** national strategy during a time of political instability, therefore without any external palliative care expertise. We reviewed training manuals, guidelines for health care professionals and community workers, data collection tools and an essential medication list. After a workshop to discuss the findings, groups were formed to revise the guidelines for health professionals and community volunteers. These now meet all international best-practice principles, and could be used in other French-speaking African countries. The workshop also led to a commitment to develop a national palliative care association in Cote d'Ivoire.

In **Botswana**, APCA carried out an organisational capacity assessment for our partner the Institute of Health Sciences Gaborone (part of the Ministry of Health). While strong governance and management structures were found, opportunities were identified to make the Institute even stronger. Recommendations included that the Institute's strategic plan be used as a management tool and reviewed six-monthly to ensure it drives palliative care implementation; that policies and procedures for all areas of operation be put in place, and a monitoring and evaluation plan be implemented.

Lesotho's Ministry of Health and Social Welfare is a keen participant in the palliative care country team established after an APCA advocacy workshop on essential pain medication. The team identified key priorities for developing palliative care in Lesotho, and APCA supported introductory training for health professionals, including pharmacists. The team has committed to the establishment of a national palliative care association, to drive the development of appropriate policies, drug availability and capacity building.

With the support of **Swaziland's** Government, APCA has drafted the country's national palliative care policy, the lack of which was causing duplication and gaps in service provision. With technical assistance from APCA, the government carried out stakeholder consultations and a situational analysis to assess service delivery. Using this input, we wrote the policy, which provides guidance in the standardised implementation of quality palliative care across Swaziland, and is now being used for developing an implementation strategy.

In **Namibia**, APCA works closely with the Ministry of Health and Social Services and Catholic AIDS Action (CAA), supporting palliative care provision in nine sites, building capacity through nurse training and mentorship and supporting policy development and national advocacy for palliative care. A tailored data collection tool was developed and 16 CAA nurses, regional managers and senior staff trained to use it in order to improve palliative care information and reporting.

"APCA is pan-African – the voice of all our members"

"The national associations meeting helped build a network of national associations: now we share ideas. I've since been in touch with colleagues for advice. And it made us feel part of APCA, really involved. The discussions were very open, so both sides know what to communicate about. We laid everything on the table and it strengthened us all.

Getting together helped us build the national associations family and made clear that APCA is pan-African – the voice of all our members. It can be a forum for members to discuss new developments; provide ongoing technical assistance and represent us outside Africa at meetings and conferences as one African voice."

Eunice Garanganga, Technical Advisor to the Hospice Palliative Care Association of Zimbabwe

ADVOCACY

APCA advocates directly with governments across Africa so that palliative care will become an unquestioned pillar of national health care provision. In line with WHO recommendations, we encourage governments to incorporate palliative care into national health policies; to ensure the availability of essential medicines (including a legislative framework that allows opioid pain medication to be accessed by all who need it); to provide necessary training and education for all health workers and the general public, and to ensure the effective integration of palliative services into society. We also advise and support national palliative care associations in their own advocacy work and help build their capacity for effective negotiating and partnering with government institutions.

After successful **capacity building** in countries such as Kenya, Malawi, Sierra Leone and Zambia, APCA has been able to focus on new countries in need of advocacy support. In Ethiopia, for example, following an earlier APCA assessment of palliative care provision across the country, we met with senior health officials to help lay the groundwork for the development of a strategic palliative care plan (including morphine availability).

We also developed assessment tools and carried out comprehensive **reviews of palliative care policies and availability** in ten African countries, including Angola, Mozambique and the Democratic Republic of Congo. These findings formed the basis for roundtable meetings with key stakeholders in each country, to review each national context and develop tailor-made national advocacy plans.

With our first **Northern Africa regional meeting**, attended by representatives from Morocco, Egypt, Senegal and Sudan, we reached new regions of the continent (Tunisia's delegates were unable to attend but we remain in contact). APCA sent an assessment guide to enable participants to gauge the state of palliative care in their countries. They then presented their findings to the meeting. Each identified challenges and with technical assistance from APCA began to formulate a national action plan for advocating for palliative care. These will be further developed at a regional conference led by APCA in Morocco in November 2010.

Where governments and educational institutions have already accepted the need for palliative care, APCA works to ensure the essential components for its provision are available: the **right medications and high-quality education**. In Botswana, we met with the Dean of the University of Botswana's new medical school about how to integrate palliative care into the curriculum. We provided technical assistance to Zambia's two-year oral morphine pilot in hospices, and we met with key stakeholders in Malawi to discuss the country's oral morphine supply chain. Participants decided that the government will be responsible for future procurement, and agreed a process through which palliative care organisations will be able to order and collect liquid morphine. APCA's guidelines for handling scheduled medicines will also be adapted to the Malawian context, to become national guidelines for handling opioids.

APCA continued to develop materials to be used as a basis for effective advocacy across the continent – including both **research-based reports and practical toolkits** to enable supporters of palliative care across Africa to engage policy makers and generate public support. We produced reports on the legal framework for palliative care in both Kenya and Uganda, covering key issues such as inheritance and family rights, and generated guidelines for handling specific WHO categories of pain-killing medications and on using opioids, to help policy-makers create safe but enabling environments for their drug supplies. We also provided support for countries in adapting existing materials to their own particular context, for example, helping Malawi adapt the opioid guidelines and Tanzania the guidelines for handling medications.

We began an ongoing project to **mitigate the impact of HIV and AIDS** in six countries through increasing access to drugs that control pain and symptoms. Working with each country, we reviewed national policies, before developing skills, materials and awareness to increase access to palliative care and essential pain-killing medications, based on our findings. Seventeen people have been trained to train others in palliative care and the use of opioids. We also reviewed the supply chain mechanism for opioids in each country, identifying gaps and recommending improvements.

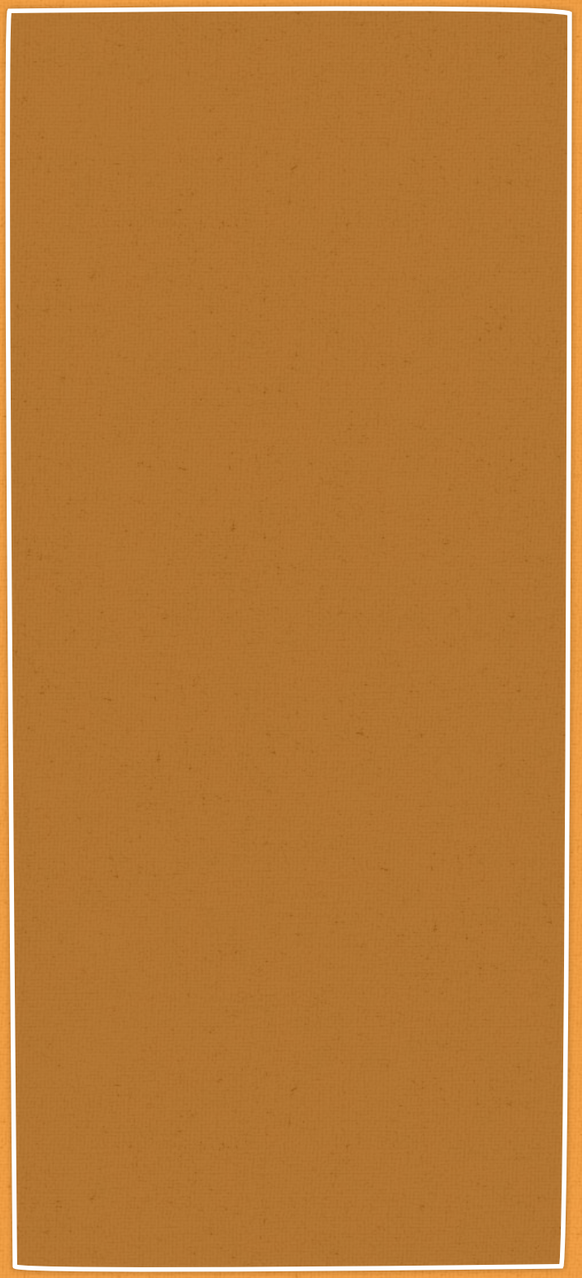
"We could have a different nation!"

'There's a stigma attached to people's understanding of the hospice service, as if our patients are in a 'group of death', just waiting to die. I often say to patients: palliative care prevents you from dying before you die; you should *live* until you die.

We often see cancer cases too late for treatment: people aren't informed of symptoms, or they're scared and turn away, or can't afford transport to a doctor. So it's especially important all doctors have palliative care training. I believe it's the backbone of cancer care in the developing world – I say to my colleagues: you can't function as a cancer expert without palliative care training. Caring for the patient doesn't mean looking at the disease alone, it means looking after the whole patient, their whole experience.

Morphine availability is so important. Only doctors can prescribe morphine here, but many are reluctant – they think it's harmful. We must make them see the need to prescribe morphine to patients in pain, and give them the know-how to do so. People underestimate the benefits of palliative care: the compassionate and the social, increasing productivity and economic capacity. My dream is to see a specialist palliative care team in each hospital. Education and advocacy are key, and they must filter right down to community level, so everyone's aware of palliative care. We could have a different nation!'

Dr Anna Nyakabau, oncologist, board member of Island Hospice Service, Zimbabwe



“If they didn’t come, there’d be no one to help”

“I felt so sad and angry when I couldn’t walk – I thought my wife would leave me!” says George Madeu, aged 73. He and his wife Juliet both burst out laughing. “He was crying and crying, but I did even think of it,” she says. “We’ve been married so long we’ve forgotten how long! I was worried afraid – I thought he was going to die. But now so happy, he’s walking and strong and can play our grandchildren.”

“When my illness began, the pain was so bad couldn’t walk,” explains George. “My skin hard as wood, there were sores all over my body. When I learned I had cancer, I lost hope. I felt depressed. Now, because of the care I’ve had from Isle of Wight Service for the past five years, the sores have cleared up, my pain is controlled and I can walk again. The nurses always ask how I’m coping with my illness, if I’m sleeping, if I have hope. If they didn’t come, there’d be no one to help.”

Although they may initially seem distant from patient care, Monitoring and Evaluation (M&E) and research are ultimately directed towards improving patients’ quality of life. They’re essential if palliative care services are to be designed so as to best address individual needs, and providers are to learn of their strengths and weaknesses, so gaps can be closed, successes replicated and patient wellbeing enhanced.

Monitoring is the systematic collection and analysis of information to track an organisation’s efficiency in achieving its goals, enabling it to compare planned and actual events by providing regular feedback that helps track costs, implementation, organisational development and financial results. Evaluation provides regular feedback on programme results, analysing information to assess an organisation’s effectiveness in achieving its goals. To ensure that APCA and Africa’s palliative care providers are learning from current practice, we monitor and evaluate our own work and that of partners, as well as building capacity in other organisations to carry out their own M&E.

We also carry out specific research projects in order to assess current provision and build a profile of need across Africa, and to ensure policies are set and decisions taken based on an accurate understanding of reality on the ground. Our results facilitate donor mapping, so resources are targeted where they can have the most impact, and double-funding of the same work from more than one donor is avoided. We present and publish our results at numerous international conferences and in journals, to share our learning as widely as possible and build support for palliative care provision for all who need it in Africa.

Building partner strength

APCA continued to provide ongoing M&E support to partners in countries including Botswana, Cote d’Ivoire, Malawi, Tanzania and Zambia, to finalise the development of their M&E frameworks, plans and data collection tools. This capacity building has enabled our partners to put in place effective M&E systems for data collection; tracking and evaluating activities, and reporting to stakeholders. APCA staff delivered introductory training courses across the continent on M&E and the role it plays in patient care, as well as week-long courses on data quality. This ensures that data gathered is meaningful, accurate and timely, so false information is not fed into the decision-making process. During 2009, 98 partner staff from 25 organisations participated in data quality management workshops in five countries, using training materials developed by APCA. These are set to be further developed into educational materials for future capacity building.

Collecting essential information

To check whether palliative care and APCA’s work are having the right impact on people with life-limiting illnesses, APCA has developed a minimum data set: a questionnaire to extract the fundamental information needed to build a profile of palliative care provision in Africa. This will allow us to identify gaps to be filled and areas of excellence to emulate. Using a specially developed tool, we carried out a pilot data collection exercise in collaboration with national associations and partners in nine African countries: Botswana, Kenya, Malawi, Mozambique, Namibia, Tanzania, Uganda, Zambia and Zimbabwe. This will become an annual data collection exercise so we can profile the trends in palliative care development across the continent, as well as helping partners to identify palliative care activities and gaps in their own countries when compared to others.

Our M&E team also supported a number of projects between APCA and partners by developing project-specific M&E frameworks and data collection tools. These projects include evaluating the added value of palliative care for HIV and AIDS patients in light of anti-retroviral therapy; the programme of small grants made to palliative care providers through APCA, supported by the True Colours Trust, and a DfID-funded project assessing palliative care policies in six countries.

Evaluating care given to children

As children have their own specific palliative care needs, APCA has driven the development of a children's palliative outcome scale (POS) for Africa – an indicator tool to measure the quality of palliative care provision in children aged 0-16. The scale takes a holistic approach, measuring change over time in areas such as pain and symptom management; distress and anxiety; communication; comfort and spirituality; carer support and family involvement. There are two versions: for children who can respond verbally and for those who are either too young or too ill to talk.

Following a literature review on the measurement of palliative outcomes in children, the tool was developed through a consultative process by a multi-disciplinary international group of experts in children's palliative care in Africa. At a Kampala workshop, the team developed an outline for APCA's African Children's POS, including target groups, domains to be measured, measuring tools and questions to be asked. The resulting draft POS was circulated for their review and refined before being piloted in several settings across Africa, due for completion in January 2011.

Informing the best end-of-life care: PRISMA

As part of an exciting consortium of international partners led by King's College, London, APCA took part in the PRISMA* research project on best practice in end-of-life care for cancer patients across Europe and in Kenya. The project coordinates research across Europe and Africa to identify cultural differences in end-of-life care, establishes a collaborative research agenda informed by public and clinical priorities, and draws together best practice and resources for quality measurement.

APCA's Kenya study covered cultural differences and public preferences in end-of-life care. We held interviews with terminally ill patients across the country to explore their perceptions and cultural interpretations of end-of-life care, illness, death and dying. These were backed up by focus group discussions with doctors, nurses and members of the public; a street survey on attitudes to end-of-life care and death, and an online survey of health professionals exploring the use of palliative outcome scales. Findings will be compared with the results of similar work across Europe, and will feed into the development of palliative care delivery in Kenya. APCA hopes to conduct future such studies in other African countries.

*PRISMA: Reflecting the Positive diveRsities of European prIorities for reSearch and Measurement in end-of-life cAre

"We all live positively," states Sinodia (right). "We're all friends, we come to the clinic to talk with each other and the nurses about our illnesses and problems, and to get medication. If I couldn't come, I'd cry. Everyone who needs it should have care like this."

"See, I'm so much stronger now. When people ask me how, I answer them: Island Hospice Service!" adds Miriam (second from right, with friends Dorothy and Lois).

> "Are we having the right impact on people's lives?"

'We monitor and evaluate our work to establish whether we're making a difference, and so we can design programmes that will bring results. We look at the quality of care individuals receive, but also at the overall impact of Island Hospice Service, how it all fits together. Does the care we give improve people's quality of life? Does our training actually increase people's capacity to deliver quality palliative care? Where are the gaps in care?

We want to bring out the perspective of the clients we serve, so we establish key indicators which will show us this and which we can track over time. We look at many statistics but we also listen to people's stories so we can flesh out the numbers. We use our findings in advocacy and we work with senior management to design programmes based on patients' experiences. M&E is central to our planning – it's not on the side, as it is at many organisations.'

Chenjerai Sisimayi, Technical Knowledge Manager, Island Hospice Service, Zimbabwe

REACHING OUT

The launch of APCA UK

APCA's Fundraising Manager – and first staff member beyond Africa – began work in September with the opening of APCA UK to raise much-needed funds for the organisation, as well as increase awareness of palliative care in Africa in general. Among our challenges are that many people in the West still don't know what palliative care is, and don't realise that it's applicable in the African context. It's not widely understood that Africa has a cancer burden as well as HIV and AIDS; nor do people realise the full extent to which people in Africa suffer from physical pain and a lack of psychological and social support. APCA is determined to start changing that, and the UK office has begun to increase international support for African palliative care.

Involving the community

Both across and beyond Africa, APCA reached out to communities to drive demand and grassroots support for palliative care on the continent. We took part in events to support World Hospice and Palliative Care Day, including fielding a team in the football tournament hosted by the Palliative Care Association of Uganda (PCAU). More than 200 people watched eight teams do friendly battle. But what do palliative care and football have in common? Teamwork, for a start. In her opening address, APCA's Director Dr Faith Mwangi-Powell said: "Just as teamwork is vital on the pitch, it's essential to delivering palliative care. No one person can deliver proper palliative care alone. It takes a team of strong family or community carers and health professionals of different disciplines – doctors, nurses, social workers and counsellors – to tackle all aspects of a patient's pain, mental and physical." And both football and palliative care make life better. Football brings pleasure and passion to many millions of people around the world, improving their quality of life. Just like palliative care.

Communicating for change

APCA continued to promote communications about palliative care in Africa that are inspiring and focused on the life-changing impact of such care – both in our own materials and by supporting others. We remain committed to giving a voice to people who need palliative care and to those working so hard to support them, who are often otherwise unheard. We gather powerful testimonies and images from people with incredible stories – both of need and of the positive impact palliative care has on people's lives. And we make sure we always talk about palliative care with passion, as a positive life-changing discipline – the kind of care everyone has a right to and deserves.

"I thought he'd die, so I'm very happy he's growing well"

Five-year-old Daniel Kuzanga is delighted with his new batch of medicines, received from a satellite clinic run by Island Hospice Service Zimbabwe at Mabvuka near Harare. "Today they've given him cough mixture and skin cream. He likes coming here – he always reminds me when it's time to take his medications," says his grandmother, Maria Rukwatura, aged 61.

Daniel was born HIV-positive, and is cared for by Maria. Both his parents have died as a result of the disease. "His mother was my daughter," says Maria. "I cared for her myself when she was sick. It was very difficult. I had counselling and training to help me cope and look after him properly. I also care for his nine-year-old brother. Daniel used to be so tiny. I thought he'd die, so I'm very happy he's still here and growing well. I hope he'll grow up strong. We've been coming here once a month for four years and they check how he is. I thank them: I feel so supported. Without this care, he would have died."

JOIN US TO CHANGE LIVES

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