



# Palliative Care ASSOCIATION OF MALAWI

## *Bulletin*

• FIRST EDITION 2009



*A cross-section of PACAM members who attended the commemoration*

## *Malawi commemorates World Hospice Day*

BY GEORGE NTONYA

PALLIATIVE CARE ASSOCIATION OF Malawi (PACAM) on 10th October joined the international community in commemorating World Hospice and Palliative Care Day.

This is the day that was set aside for governments, non-governmental

organisations and members of the community to reflect on the activities aimed at improving the quality of life of people suffering from incurable diseases including cancer, and to renew their commitments to reduce the suffering of such people.

PACAM held its commemorative activities at Crossroads Hotel in Lilongwe.

The activities included traditional

dances by Kwacha Cultural Troupe, presentations by some palliative care institutions and comedies.

Guest of Honour at the function Immaculate Kambiya, who is National Palliative Care Coordinator in the Ministry of Health, commended members of PACAM for sparing their time to do voluntary work, which is improving the

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## *PACAM develops palliative care curriculum for CHBC*

A LOT OF PATIENTS SUFFER SILENTLY IN THE COMMUNITY from life threatening diseases like cancer and other HIV related conditions, Director of Nursing Services in the Ministry of Health Sheilla Bandazi, has said.

Bandazi was speaking when she opened a four-day workshop to develop a curriculum for the training of community

home based palliative care volunteers in Malawi.

Organised by Palliative Care Association of Malawi (PACAM), the workshop took place at Korea Garden in Lilongwe between 4th and 7th August 2009. It drew participants from different institutions including Lighthouse, Queen

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# Message from the Editor

Dear Readers,

WELCOME TO OUR FIRST EDITION OF THE Palliative Care Bulletin. It is my hope that you will find this bulletin more informative and educative on a wide spectrum of health issues and particularly on the concept of palliative care, which is new in Malawi.

In this edition we will take you through the story behind Palliative Care Association of Malawi (PACAM), issues of life threatening diseases and the interventions which are being implemented to improve the quality of those with chronic illnesses.

We would like to invite articles, letters or any comments on health issues in your area, community or work place so that this bulletin acts as a platform for sharing of experiences and ideas.

We hope that as we go along, this bulletin will become richer not only in terms of story content, but also in terms of quality.

If you also have questions about palliative care, do not hesitate to write to us and people with expert information will provide the necessary answers.

We look forward to hearing from you through your articles, letters, and opinions.

We would be most grateful if you could enclose a publishable photograph of yourself when you are submitting an article for publication in this bulletin.

Send all correspondence to:

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You can also get some information about PACAM and its activities on its website:

[www.palliativecaremw.org](http://www.palliativecaremw.org)



*Participants to the CHBC curriculum development workshop*

Elizabeth Central Hospital (QECH) and the College of Medicine.

Bandazi told the participants that the workshop was important because patients with life threatening diseases, who are usually looked after in the community, suffer disproportionately higher disease burden than patients suffering from other disease conditions.

"Though we don't have exact figures, it is known that a lot of patients suffer silently in the community from life threatening diseases like cancer and other HIV related conditions. As such, development of this palliative care curriculum for community home based care volunteers' training is timely and since it is going to accelerate the scale-up of cost effective palliative care interventions in the community considering that we have limited resources," she said.

She said that many patients with life threatening diseases report to health facilities late because of some traditional and cultural practices, hence the need for community home based care volunteers to be well trained to provide quality care.

She commended PACAM for taking the initiative to ensure that the community home based care volunteers get requisite training.

"As a ministry, we believe community initiatives are essential and are

*...it is known that a lot of patients suffer silently in the community from life threatening diseases like cancer and other HIV related conditions*

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quality of life of the chronically ill patients.

She assured that the Ministry of Health would ensure that strong pain relief medicines such as morphine are available in health facilities.

Kate Musimwa from Pact Malawi, one of the organisations that fund PACAM, also commended PACAM for the good job it is doing.

She assured the organisation continued support.

However, she urged PACAM secretariat to take advantage of World Hospice and Palliative Care Day to bring together prospective partners so that they hear for themselves the good work being done by palliative care volunteers.

Chairperson of PACAM Board of Trustees Sr. Anne Carr said that people with chronic diseases have a right to quality life and there is need for advocates to join hands to ensure that the patients are not denied this right. She urged the palliative care volunteers to continue with the good work.

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among important strategies to allow all people access timely palliative care services. I am pleased that this workshop will look into that area and come up with cost effective approaches to be taught to volunteers," Bandazi said.

The participants agreed to merge the training manual on palliative care, which was developed and pre-tested in 2007, with the one on home based care, instead of having two separate sets.

Among the topics in the new curriculum are signs and symptoms of cancer, the concept of palliative care, psycho-social support, communication and counseling.

# PACAM annual report

## 2007 - 2008

THE 2007-2008 ANNUAL REPORT OF THE PALLIATIVE CARE ASSOCIATION OF Malawi (PACAM) has 12 pages and focuses on a number of issues which include drug availability, education, service delivery and networking.

On the first page of the report there are two messages, one from chairperson of the trustee (2006-2008) and another from the chairperson of the Board of Directors for the same period.

In her message Sister Anne Carr, then chairperson of the Trustees, says that perhaps palliative care is one of the most needed services in the health reality of Malawi today.

"We are aware that so many of our people die in hospitals and in the villages. We are aware that many are going through great pain and anguish with very little care. There is no one to relieve their suffering; they have no one who will comfort and support them," writes Sr. Carr.



Sister Carr

She says that there is nothing so distressing as seeing a child of three or four suffering the agony and mental torture incurred by cancer, burns or HIV/AIDS.

"These cases are on the increase. More and more money is being poured into the diagnosis of HIV/AIDS. Little is being done to follow-up such people, alone in their homes," she laments.

On a very serious note, Sr. Carr says that palliative care addresses the agony and anguish of our people, our relatives and above all sons and daughters of God. Palliative care helps patients feel

accepted, loved cared for and their health is being monitored.

With palliative care patients are helped die in peace with their God, relatives and friends and with themselves, in their homes, she says.

"Happy are those who care for the dying!" she concludes.

Chairperson of the board for the period Lameck Thambo starts by thanking God for His support in what he describes as a busy and challenging year.

He says that the organisation's strategic plan steered it in a clear and focused direction.

He also thanks all the directors, trustees, members and PACAM partners, both local and international, for their ongoing support.

"We are most grateful to all our donors who have supported us and kept PACAM going. I also extend special thanks to Jessica Mackriell who has been working very

hard in coordinating all PACAM activities," he says.

Thambo says that PACAM has every reason to be optimistic about the future.

"PACAM will continue to value and rely upon your support as it implements its work programmes in the years ahead," Thambo writes.

On drug availability, the report says throughout the health sector, drug availability is a difficult issue. This is not different in palliative care.

"There is limited understanding of the cost and sustainability of opiate preparations, though morphine (either as oral morphine liquid or slow release tablets) has been available at limited sites since 2004," the report says.

Laxative stock-outs have sometimes hampered best practice, it says adding that earlier in the year PACAM collaborated with the Ministry of Health's pharmacy department to address some of the issues.

Key policy makers and representatives from provider institutions met to discuss suitable import quotas, systems for procurement, reporting and distribution. They recommended that oral morphine liquid and slow release tablets should be made available at all health institutions in Malawi.

On page four the report talks about education in palliative care, whose strategic objective is to establish and support standardized and accredited training.

It says that PACAM directors had to take time out of their jobs to train participants in a series of five-day "Introduction to Palliative Care" courses. The courses were held across the country.

One of PACAM's priorities has been to increase the number of people qualified to train others in palliative care.

In August 2007 PACAM produced a five-day training manual in collaboration with the Ministry of Health, in line with the organisation's strategic plan for a standard curriculum to be used in the training of health care workers.

The manual was developed over the course of four workshops held in February, May, June and August. The manual was pre-tested at a training course in October before being approved by the ministry.

In September 2007 PACAM also organized a master trainers' course in Blantyre. The course covered teaching methodologies as well as principles of palliative care.

The 13 people that attended the course were certified by the Ministry of Health and PACAM to teach during the training-of-trainers (ToT) courses.

On service delivery, the report says that PACAM directors carried out eight sensitization visits to health facilities in all the three regions of the country, as part of PACAM's advocacy strategy and in response to requests from different district hospitals for more information about palliative care.

These visits typically involve a brief presentation on the philosophy of palliative care, palliative care in Malawi and PACAM.

"Several visits were made with Dr. Gigsby, a pain specialist visiting from USA," says the report.

Hospice Africa UK funded the visits.

On networking, the report says that individuals and organizations showed interest to join PACAM. The association's membership grew by about 60 percent to 220 people between March 2007 and March 2008.

Palliative care interest groups have been established and several meetings have taken place, where specific patient cases have been discussed.

On 5th October 2007 a total of 250 people commemorated the World Palliative Care Day to raise awareness about the need for palliative care in Malawi. PACAM held a national event in Lilongwe under the theme "Care across the ages."

The audience described the event as inspiring and informative. PACAM was also represented at the second palliative care conference of the African Palliative Care Association, which took place in Nairobi, Kenya between 19th and 21st September 2007.

PACAM was also represented at the summit of the Worldwide Palliative Care Alliance, also held in the same month in Nairobi.

On page 9 the report focuses on organization development. It says that in view of the strategic objective to establish a policy and procedure framework that would ensure a sustainable secretariat to effectively coordinate palliative care activities in Malawi, the Board of Directors decided in August that there was an urgent need for a human resource assessment and development.

In December a consultant was hired. He developed PACAM's structure, terms of reference and a human resources manual.

The directors met three times in 2007.

The report notes financial assistance and contributions provided by Help-the-Hospices, Africa Palliative Care Association (APCA), Pact Malawi, Lighthouse Trust, Ndi Moyo, Palliative Care Support Trust and Umodzi Palliative Care.

The financial summary covering the period April 2007 and March 2008 shows that PACAM had a total income of K5,699,004 against total expenditure of K4,214,171.

# PACAM achievements

## April- December 2008



*Development of African Palliative Care Standards in Uganda*

ON 3RD MAY REPRESENTATIVES OF THE MINISTRY OF Health met with PACAM directors to review a training manual on palliative care which was developed and pre-tested in 2007.

They made final amendments to the manual. After the amendments, the manual was ready for printing and distribution.

On 23rd June officials from the Ministry of Health and PACAM met in Lilongwe to discuss plans for a training-of-trainers course.

It was agreed that participants should be doctors, registered nurses, community nurses, clinical officers and dental technicians. They should have completed a 5-day palliative care introductory course or its equivalent and have practical experience of palliative care.

The training was to be facilitated by "master trainers" who had been identified and accredited.

They also agreed that the national manual for palliative care and the home based care trainers manual should be used during the course.

In May the new PACAM national coordinator Lameck

Thambo, introduced over 153 health care workers to the concept of palliative care. The health care workers were from Balaka, Chikwawa, Mwanza, Thyolo, Mulanje and Mwaiwathu hospitals.

At each health facility Thambo delivered a 30-minute power point presentation, encouraging health care workers to integrate palliative care into the existing services.

The health care workers were able to ask questions on how to set up palliative care clinic, where to access morphine, how to become PACAM members and other issues.

In the same month Thambo was able to meet with five "District Health Management Teams in the southern region to advocate for the inclusion of palliative care in the annual District Implementation Plans.

The most significant outcome of the meetings was the establishment of a working relationship which resulted in PACAM providing technical assistance.

As of June Malawi had no national guidelines or standards for palliative care. PACAM had been seeking ways to begin the process for the development of the standards and with support from the Ministry of Health organised a five-day work-

*The home based care supervisory checklist was reviewed and some palliative care indicators were incorporated...*

shop in Lilongwe where a draft was developed

In May and June PACAM national coordinator Lameck Thambo assisted in the coordination, identification of facilitators and the actual facilitation of training courses run by the Ministry of Health and Lighthouse.

He also helped Ndi Moyo Palliative Care in Salima and Kamuzu Central Hospital with planning and proposal writing.

Between April and June PACAM strengthened its networking. A total of 66 individuals and one organization registered to become members of the association, bringing the total membership to 220.

A regional update meeting for palliative care stakeholders took place on 25th April at the Malaria Alert Centre in Blantyre. A total of 42 people attended the meeting, one of a series of meetings that serve as networking forums.

Participants comprised doctors, clinical officers, nurses, dental therapists and environmental health officers.

The programme included presentations on pain assessment, the analgesic ladder and the use of morphine. The presentations were supported by case studies and a video documentary on oral liquid morphine.

A similar meeting also took place on 30th May in the University of North Carolina (UNC) conference hall in Lilongwe and 40 health care workers from different institutions attended.

A number of activities took place in June. Andre Wagner from Hospice Palliative Care Association arranged a training programme for PACAM board members. The programme covered such topics as fundamental policy and procedure identification and development, human resource management and the organizational development process.

The directors expressed their appreciation for the skills they gained.

The board of directors and staff from PACAM secretariat met for two days in Blantyre to review policies and procedures for the secretariat. Wagner also facilitated the meeting.

The board also held an extra-ordinary meeting to address some of the concerns raised about the organization structure. The board then approved a 'Board Manual', Financial Policies and Procedures as well as 'Employee Manual'.

Richard McKenna, an English communications consultant had a meeting with secretariat staff and representatives of the directors to draft a realistic fundraising strategy. Target sectors were identified and appropriate

fundraising activities suggested.

Essential Marketing won the contract to develop the website for PACAM and the web designer attended parts of a three-day corporate image workshop.

Richard Kaye from African Palliative Care Association and Alex Magezi from Hospice Palliative Care Association facilitated a five day workshop in Lilongwe, which brought together representatives of PACAM directors, secretariat staff and other stakeholders.

Participants were trained in monitoring, evaluation and research (MER) and the workshop resulted in the development of MER plan for the secretariat.

The board of directors met on 6th May. They discussed policies and procedures and agreed on a process for nominating directors to represent the board at meetings and workshops. They also elected new office bearers

In terms of secretariat operations, the directors recruited three full time staff for the secretariat, namely the national coordinator, operations manager and finance/administration officer.

At the end of June the office transferred from Blantyre to Lilongwe.

World University Services of Canada (WUSC) launched the 'Palliative Care Field Guide for Community Volunteers' on 28th November and PACAM was given the responsibility to distribute the first 500 copies and to coordinate the translation and production of a Chichewa version.

A meeting of district community home based care coordinators, zonal coordinators and officials from the Ministry of Health took place at Kalikuti Hotel in Lilongwe between 5th and 7th November.

Participants agreed that home based care coordinators in the districts should incorporate palliative care and that those who had not been trained in palliative care should be included in the next training programme.

The home based care supervisory checklist was reviewed and some palliative care indicators were incorporated.

In December PACAM conducted a two-day training to equip participants with basic advocacy skills for rolling out palliative care service delivery in Malawi based on World Health Organisation (WHO) public health strategy.

Dr. Henry Ddungu from the African Palliative Care Association and PACAM national coordinator Lameck Thambo facilitated the course. Participants comprised journalists, health care workers, private sector players and trainers from health institutions.

## *A look at PACAM annual general meeting*

PACAM HELD ITS FIRST ANNUAL GENERAL MEETING (AGM) on 18th October in Lilongwe City.

Dr. Faith Mwangi-Powell from the African Palliative Care Association delivered a key note speech. She described the importance of palliative care across Africa and the role that national associations can play.

Sister Anne Carr, director of the interdenominational Pastoral Care Centre and chairperson of PACAM board of Trustees talked about palliative care services in Malawi.

She talked of how palliative care has reduced the agony and anguish of the people.

Tiyanjane Clinic of Blantyre, Ndi Moyo of Salima and Lighthouse in Lilongwe presented their experiences at the AGM.

A palliative care patient whose severe pain was being managed with morphine also explained how palliative care had improved the quality of his life.

Matron Immaculate Kambiya, the national Palliative Care Coordinator at the Ministry of Health assured that govern-

ment was committed to developing palliative care services.

Kate Musimwa represented the United States Agency for International Development (USAID) and its cooperating agency - Pact Malawi- who funded the meeting. Musimwa commended PACAM for its efforts to alleviate the suffering of chronically ill patients

PACAM directors presented the annual report, detailing achievements in the focus areas of drug availability, education, service delivery, networking and organization development.

They reported that they were developing a new strategy which would become effective in January 2009.

The AGM was an opportunity for care providers to ask questions face-to-face to the directors. Members also had an opportunity to ask about the possibilities for further training.

They encouraged PACAM to advocate for drug availability for palliative care patients.



*A meeting on the introduction of palliative care in pre-service curriculum*

# *PACAM's historical background*

PALLIATIVE CARE ASSOCIATION OF MALAWI (PACAM) WAS established in September 2005 to support, develop and promote affordable and culturally appropriate palliative care in Malawi.

PACAM has a joint programme with the African Palliative Care Association (APCA) to strengthen local capacity in the provision of comprehensive palliative care services. APCA provides PACAM with technical assistance and this is being achieved using a strategy that incorporates advocacy for palliative care at local and national levels, training, mentorship and supervision of service providers in palliative care delivery.

Malawi has an estimated population of 13 million people and over one million of them are infected with HIV, the virus that causes AIDS. Out of the total population, at least 25,000 people have cancer.

Most of the HIV infected people and cancer patients are in need of palliative care, a concept which is becoming widely recognized as a vital intervention to improve the quality of life of HIV positive people, cancer patients and others with life-threatening illnesses.

There is an increasing body of research, both internationally and within Africa, supporting a call for improvements in the quality of, and access to, palliative care in different countries.

PACAM, as a country-wide coordinating and facilitating body, is undergoing continued organizational development through human resource strengthening, policy and procedure development, and programme implementation to ensure on-going quality improvements in its work.

In all the project areas, PACAM is engaged in a relationship with APCA where it receives on-going technical assistance to strengthen its own capacity to coordinate and promote palliative care in Malawi.

One of PACAM's goals is to contribute to the national HIV/AIDS response by supporting the scale-up of palliative care services in Malawi. Therefore, PACAM is working across the country.

PACAM has continued to work hard to build the capacity to grow effectively.

For example, in February 2009 PACAM was involved in activities which focused on the training and education aspects of palliative care. In collaboration with the Ministry of Health it ran a workshop to continue developing and to finalise the national palliative guidelines.

The National Coordinator was invited to a meeting in Uganda organized by APCA to discuss various issues pertaining to palliative care education within the region. The meeting brought together palliative care education experts from across Africa. And following the meeting, PACAM facilitated a five-day workshop organized by PACT for 19 grantee sub managers who coordinate home based and palliative care programmes.

PACAM boasts a trained board of directors and it has revised policies and procedures, revised its logo and corporate image. It has also a clear monitoring and evaluation (M&E) framework for all its work as well as a fundraising strategy and a website.



*National Coordinator, Lameck Thambo, receives a certificate after attending a Monitoring and Evaluation workshop*