



ANNUAL REPORT

2014

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Abbreviations & Acronyms

AIC	-	African Inland Church
AIDS	-	Acquired Immune Deficiency Syndrome
APCA	-	African Palliative Care Association
CME	-	Continuos Medical Education
DH	-	District Hospital
Dr	-	Doctor
FBO	-	Faith Based Organisation
FRACODEP	-	St. Francis Community Develpoment Program
HAU	-	Hospice Africa Uganda
HCK	-	Hospice Care Kenya
KICOSHEP	-	Kibera Integrated Community Self-Help Programme
KNH	-	Kenyatta National Hospital
L5H	-	Level 5 Hospital
MOH	-	Ministry of Health
NCDC	-	National Centre for Disease Control
PCC	-	Palliative Care Centre
PCEA	-	Presbyterian Church of East Africa
PFHI	-	Pain Free Hospital Initiative
PGH	-	Provincial General Hospital
THET	-	Tropical Health and Education Trust
TRH	-	Teaching Referral Hospital
USA	-	United States of America

Communication from Dr. Zipporah Ali, Executive Director



Palliative care should not be seen as a luxury, but as a necessary essential service; it should not be only for the few who can afford it, or for those living in better socio-economic conditions, it should be for all in need. The Kenya Hospices and Palliative Care Association (KEHPCA) works together with its stakeholders such as the Ministry of Health, government hospitals, mission hospitals, hospices, community based organizations, the public as well as training institutions to ensure that there is greater access across the country. In the past 7 years there has been a significant improvement in palliative care in Kenya focusing on: availability; accessibility and affordability of services through scaling up existing services as well as integrating palliative care into the public health care system.

As a national association advocating for palliative care in Kenya, KEHPCA is challenged by an enormous need for services, education and training of health care professionals, the public and policy makers, and accessing essential medicines for pain relief and symptom control. Kenya's population is 43 million people and cancer and HIV/AIDS are the leading causes of death. The Ministry of Health (MoH) of Kenya estimates 30,000 new cancer patients per year, 28,000 of whom will die within two years of their diagnosis. Over 80% of these patients present with advanced illness and are candidates for palliative care. The current prevalence of HIV/AIDS is 5.8%, some present with advanced illness requiring palliative care services. In Kenya Non-communicable diseases (NCDs) account for more than 50% of total hospital admissions and over 55% of hospital deaths. Clearly, there is a great need to prioritize palliative care and pain relief in Kenya, as most patients affected by NCDs and other diseases like HIV/AIDS will benefit from palliative care and pain relief.

Recognizing the voice of the community is important in palliative care. In Kenya, a project on empowering patients and their families to recognize their palliative care rights (access to palliative care services; access to appropriate pain medications; the right to choose one's power of attorney, the right to make a will; making successions plans for one's children) is ongoing. Unless the community is empowered to understand the benefits of palliative care services; it remains a service for just but a few who are aware. KEHPCA and its partners are using powerful messages that are friendly to the community to create awareness on palliative care as a right for those in need.

Communication from Dr. Zipporah Ali, Executive Director

Several other initiatives are being taken to improve palliative care for both adults and children in Kenya. These include National Palliative Care Guidelines that have been developed; integrating palliative care into the public healthcare system (government hospitals); integrating palliative care in undergraduate medical and nursing curriculum; integrating palliative care in the National Cancer Control Strategy and the National Guidelines for Cancer Management as well as in the Kenya National Strategy for the Prevention and Control of Non Communicable Diseases. In 2014, the Ministry of Health procured over 22 kilograms of morphine (used to control moderate to severe pain) which is the first time in the history of Kenya.

There are several challenges that need to be addressed. Currently, palliative care is not included in the national health budget or the county budgets, thus making it a big challenge: to train health care professionals; set up palliative care units; ensure that all essential medicines for palliative care are available. Palliative care is mostly offered by hospitals and hospices. There remains a great need to have it offered at the community level including health centers and dispensaries through partnerships with community health workers. There is still a great need to train and educate health care professionals so as to empower them with the skills and knowledge needed to offer quality palliative care services, and, at the same time, there is a great need to create awareness to the public so that they can seek services as there is an under use of existing services.

KEHPCA wishes to say a big ASANTE SANA (Thank you) to all its members, friends, stakeholders, Ministry of Health of Kenya and the donors who continue to support hospice and palliative care across the country. Special appreciation goes to those who take care of patients and their loved ones, thus bringing comfort and peace into their lives. You are great people!

As Kenyans, we need to work together to ensure accessibility, availability and affordability of palliative care and pain relief for all in Kenya. Palliative care is everyone's business: my business, your business, our business. We all Care. Pamoja (together) we can make a difference. Join us in making this difference.



Dr. Zipporah Ali
Executive Director

Case Study: Paediatric Palliative Care, Homa Bay County

KEHPCA has been working closely with Homa Bay to integrate paediatric and adult palliative care services in their hospital. This has led to alleviating the pain of patients suffering from life threatening illnesses in their region. Below are some of the remarks from the beneficiaries and providers of these interventions:



“Before we established a play room children used to just lie in bed idle and in pain, nowadays they are preoccupied by toys, cartoons, books. This has greatly improved their care”

“We were referred from another hospital because they could not manage my son. Here at Homa Bay they did the test and confirmed that he has sickle cell disease. He was in a lot of pain but now it is well controlled by morphine”

“With the training we have received from KEHPCA, we are able to identify patients who require palliative care and manage their symptoms appropriately”

Service Delivery

Kenya Hospices and Palliative Care Association (KEHPCA) aspires to promote access of quality palliative care for all Kenyans and their families faced with life threatening illnesses by promoting and supporting acceptable, accessible and affordable quality palliative care services.

Provision of palliative care requires a multidisciplinary approach and encompasses; pain and symptoms control, proper communication, psychosocial support, spiritual care, end of life management, bereavement and legal intervention. The services are accessible to adults and children and provided to both inpatient and out patients.

The association has been supporting scaling up palliative care services and strengthening the existing palliative care providers through; capacity building health and non healthcare workers, mentorship, advocacy, setting up and providing palliative care guidelines. It is through these interventions that there has been an increase in number of palliative care providers and patients accessing services. In 2013 4,762 patients accessed services in the 11 level 5 public hospitals, in 2014 7,128 patients were served representing a 49% increase.

Capacity building involves training on palliative care and clinical placement. This enables the participant gain knowledge, skills and attitude towards service delivery to enable them identify patients who require services, provide the necessary care and refer appropriately.

The Association has been advocating to the county and hospital administrators to recognize and allocate resources toward palliative care. This has led to some hospitals and counties to include palliative care in the budget, availability of essential medicines and setting up of palliative care services in non existing facilities. This has enabled patients and their families to access services without travelling for long distances.

KEHPCA has been working with interested partners including county governments to help in setting up of palliative care units through; renovations and equipping of the identified space. This has helped in ensuring there is proper coordination of services and availability of conducive environment for service delivery. Provision of services is guided by the National palliative care guidelines which was developed and launched by KEHPCA and Ministry of health in 2013.

“we appreciate your feedback on the medicine we gave you. We are happy that the smell and pain has subsided and now you are able to sleep and interact with other people without discomfort” quote from palliative care nurse.

Capacity Building

One of KEHPCAs area of focus is education and training. The main aim is to build a pool of healthcare/non healthcare workers with a change of knowledge, skills and attitudes in palliative care. This in turn leads to quality palliative care offered to patients and families faced by life threatening illnesses.

Capacity building has been done through:

- Training
- Modular training
- Supporting specialized training
- Continuous Medical education (CME)
- Mentorship

Training is done based on the needs of the trainee hence modular training has been done in several institutions including Moi Teaching and Referral Hospital. Once completed, participants are awarded with certificates. Pharmacists are also included in the training so as to enhance team work.



Group photo of pediatric palliative care trainees

Through Treat the Pain program (American Cancer Society), healthcare workers were taken through pain management modular training at Kenyatta National Hospital (KNH) dubbed Pain Free Hospital Initiative (PFHI). This was done systematically by the KNH pain and palliative care unit and will end in September 2015 after reaching out to all departments. This training is hoped to improve pain management at the hospital and will later be rolled out to other health facilities.

Capacity Building

CONTINUOUS MEDICAL EDUCATION

Continuous Medical Education (CME) sessions are also noted to be important in scaling up palliative care services. These were done specifically targeting doctors and other healthcare workers on topics addressing needs identified by the palliative care workers in the institutions and regions.



Continuous Medical Education session in Kitale

Hospitals and hospices with palliative care training have been offering mentorship to the new palliative care units at the level four hospitals thus strengthening referral systems. Healthcare workers have also been supported to pursue specialized training in palliative care including the recently launched Kenya Medical Training College 18 month distance learning diploma in higher education in palliative care. 16 students have been supported through Hospice Care Kenya (HCK).

Through Tropical Health and Education Trust (THET), healthcare workers have been supported to pursue diploma/degree in palliative care.

Through capacity building there has been significant increase in number of patients accessing services.

DISSEMINATION OF ONCOLOGY AND PALLIATIVE CARE DOCUMENTS

KEHPCA together with the Ministry of Health developed and launched several national palliative care documents in 2013. KEHPCA, MOH with support from The True Colours Trust, conducted dissemination sessions within counties already integrating palliative care services.

Some of the documents that were disseminated included; National cancer management guidelines, National palliative care guidelines, Trainers and trainees manual, Palliative care training curriculum and the Legal aspects in palliative care handbook.

Each hospital was received hard and soft copies of the documents. Four dissemination activities were done with a total attendance of 189 participants from 49 health facilities across the counties.

The documents will enable the hospitals provide holistic palliative care services based on national standards.



Partnerships & Networking



FHSSA
Compassion has no borders



American Cancer Society
A program of the American Cancer Society



The True Colours Trust



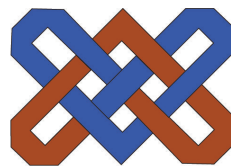
International Association for the Study of Pain



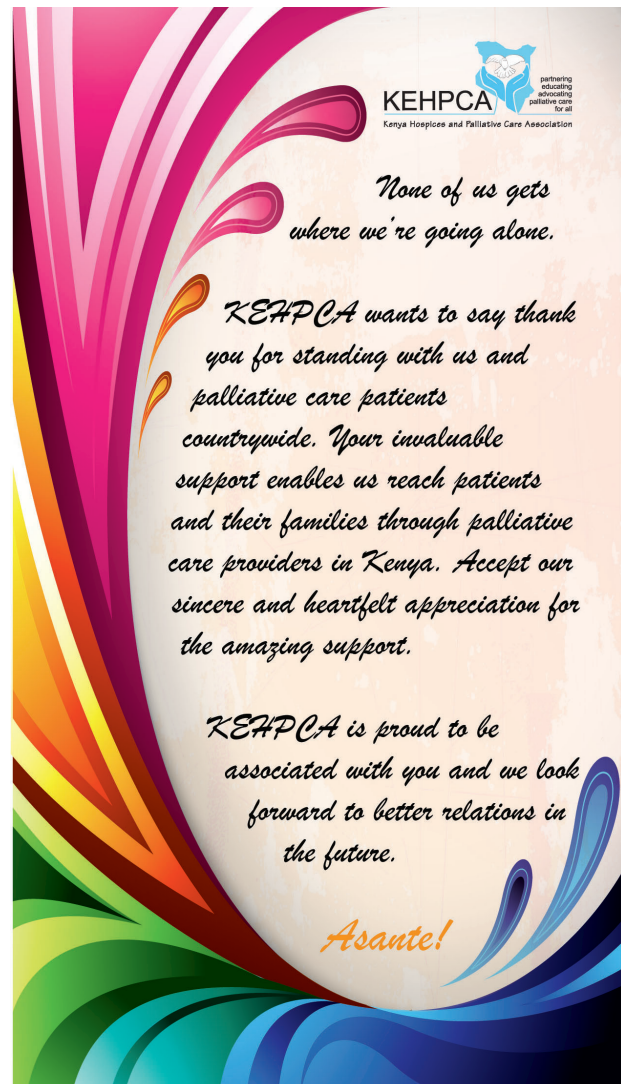
Ministry of Health



icpcn
international children's
palliative care network



Hospice Care Kenya



Monitoring & Evaluation

KEHPCA instituted several mechanisms to monitor the progress of palliative care for the year 2014. The national association has a strategic plan (2012- 2016) with detailed goals and directions which forms the basis for KEHPCA's plans. This has ensured tracking of the organizations' objectives which enabled the achievement of KEHPCAs goals for the year.

KEHPCA collects data from the palliative care providers across the country every month. The data captured is analyzed and it helps provide information on existing gaps, program design and decision making. A comparison of the number of patients served in the ten provincial and level 5 hospitals that KEHPCA supported to integrate palliative care services showed increased number of patients who received palliative care from 4762 in 2013 to 7024 in 2014. This information is also shared with the Ministry of Health (MoH) to advocate for palliative care and allocation of resources.

Activity reports from various activities undertaken by the national association are usually compiled and send to partners, MoH and other stakeholders to inform on work progress. The activities that KEHPCA undertakes include; training in palliative care, continuous medical education (CME) in various hospitals, support supervisory visits, mentorship for various palliative care providers and palliative care advocacy and awareness creation targeting the general public, policy makers and stakeholders.

Pain management is a key component of palliative care delivery. Morphine; an opioid, is a medicine used in the management of severe pain. This medicine is used as a marker of palliative services uptake worldwide. The pharmacy and poisons board is the body that monitors the importation and utilization of morphine and other medicines. Periodically, KEHPCA collects information from the board which in 2014 confirmed an increase in morphine consumption in Kenya. This, therefore, confirmed the increased number of patients accessing palliative care and as well more patient's pain being managed using opioids.

Integrating Legal and Ethical Aspects in Palliative Care

People facing life-threatening illnesses are deeply vulnerable: often in severe physical pain, worried about death, incapacitation, or the fate of their loved-ones. Legal issues can increase stress for patients and families, and make coping harder impacting on the quality of care. In the absence of a clear legal provision expressly recognizing Palliative care in Kenya, providers may face numerous legal and ethical dilemmas that affect the availability, accessibility and delivery of palliative care services and commodities.

In order to ensure positive outcomes for patients, palliative care service providers should be able to identify various needs of patients and their families including specific issues requiring legal advice and interventions. Access to legal services remains a big challenge in Kenya, with limited availability of specialized legal services for health related legal issues. Increased awareness on the benefits of legal services in palliative care will drive demand for easily accessible and more affordable direct legal services to address legal issues for a more holistic approach to quality palliative care.

Article 43(1) (a) and Article 48 of the Constitution of Kenya 2010 guarantee respectively the right to the highest attainable standard of Health and access to justice for all. Integrating legal services in health service delivery should include the opportunity of getting legal interventions not only in the way of claiming the protection of palliative care (such as securing access to health and social benefits) but also in the face of dealing with other life-transactions of the patients and their families (such as protecting and disposing of property; planning for children and other dependents). Legal services may equally provide critical support to practitioners' to mitigate against ethical grievances and legal disputes.

KEHPCA has partnered with KELIN to progressively scale up integration of legal services in palliative care. This has been done through various initiatives including awareness creation by means of talks and open fora, reading materials and conducting training sessions. Building on this work, KEHPCA and KELIN facilitated a legal workshop during the 4th National palliative care conference 2014. A panel of legal and health experts; working with palliative care patients and families in various hospices in Kenya led discussions during the successful workshop which attracted over 150 delegates. There is need for continued advocacy for the integration of legal support in palliative care service delivery in Kenya for the benefit of health service providers, patients and their families.

Financial Report

Kenya Hospices and Palliative Care Association

(A company limited by guarantee)

Report of the directors

For the year ended 31 December 2014

The directors submit their report together with the audited financial statements for the year ended 31 December 2014, which show the state of the organization's affairs.

1 Incorporation

The association is duly registered in Kenya under the Companies Act (Cap 486) and is limited by guarantee.

2 Principal Activity

The principal activity of the association continues to be that of promoting and supporting acceptable, accessible and affordable quality palliative care throughout Kenya.

3 Results

	2014 Kshs	2013 Kshs
Total income	38,368,634	46,296,235
Total expenditure	(44,119,184)	(50,449,059)
Deficit for the year	<u>(5,750,550)</u>	<u>(4,152,824)</u>

4 Financial statements

At the date of this report, the directors were not aware of any circumstances, which would have rendered the values attributed to the assets in the financial statements misleading.

5 Reserves

The reserves of the trust are set out on note 11, 12 and 13 of these financial statements.

6 Directors

Mr. Peter Bunde	- Chairperson
Mr. Faustin Mgendi	- Honorary treasurer
Mrs. Roselyn Opindi	- Honorary secretary
Dr. Zipporah Ali	- Executive director
Dr. Esther Munyoro	- Member
Mrs. Safarina Gichohi	- Member

The articles of association provide for the retirement of one-third of the directors by rotation.

7 Directors' benefits

Since the last Annual General Meeting of the association to the date of this report, no director has received or become entitled to receive any benefit other than amounts received under employment contracts.

8 Auditor

The association's auditor, MAZARS (Certified Public Accountants (K)), has indicated willingness to continue in office in accordance with section 159(2) of the Kenyan Companies Act (Cap 486).

By order of the board



4/8/2015

Financial Report

Kenya Hospices and Palliative Care Association
(A company limited by guarantee)
Statement of financial position
For the year ended 31 December 2014

	Note	2014 Kshs	2013 Kshs
Assets			
Non-current assets			
Property and equipment	8	<u>19,273,440</u>	<u>9,678,566</u>
Current assets			
Receivables	9	1,565,911	1,437,604
Cash and cash equivalents	10	<u>25,637,873</u>	<u>22,752,961</u>
		<u>27,203,784</u>	<u>24,190,565</u>
Total assets		<u>46,477,224</u>	<u>33,869,131</u>
Fund balances and liabilities			
Fund Balances			
Property fund	11	2,267,698	2,255,145
General fund	12	18,929,166	9,521,545
Designated fund	13	<u>6,688,055</u>	<u>21,760,104</u>
		<u>27,884,919</u>	<u>33,536,794</u>
Non Current liabilities			
Borrowings	15	<u>4,865,692</u>	<u>-</u>
Current liabilities			
Payables and accruals	14	726,614	332,337
Deferred Income	16	<u>13,000,000</u>	<u>-</u>
		<u>13,726,614</u>	<u>332,337</u>
Total fund balances and liabilities		<u>46,477,224</u>	<u>33,869,131</u>

The financial statements on pages 6 to 19 were approved for issue by the directors on 4/8/2015 2015 and signed on its behalf by:-

Director



Director



Palliative Care Conference

The fourth edition of the National Palliative Care Conference – a biennial event organized by the Kenya Hospices and Palliative Care Association - was held between 12th and 14th November 2014 in Nairobi, Kenya. 300 delegates from all nine countries - Kenya, Uganda, Rwanda, Malawi, Nigeria, Australia, Canada, the USA and the United Kingdom - came together to discuss palliative care provision under the theme, “palliative care is everyone’s business.”



Kenya Hospices and Palliative Care Association Executive Director Dr. Zipporah Ali got the conference underway with a welcome note that gave a breakdown of palliative care while emphasizing the need for basic training of palliative care to medical students.

Cabinet Secretary Ministry of Health Mr. James Macharia officially opened the conference while noting that life threatening diseases used to be perceived as a particular group’s problem but are slowly cutting across all divides. He added that, “it is the government’s desire for palliative care to be integrated to all levels including community levels thus ensuring patients have access to services closer to their homes.” Professor Anne Merriman founder of Hospice Africa Uganda and a Nobel peace prize nominee spoke on the value of compassion to palliative care. “Compassion is the emotion of empathy that one feels in response to the suffering of others that motivates help.”

The Executive Director of the Africa Palliative Care Association Dr. Emmanuel Luyirika nicknamed “the father of palliative care in Africa” spoke extensively on the need for strengthening of palliative care by engaging the government and working in collaboration with the World Health Organization.

Palliative Care Conference



Professor Scott Murray university of Edinburgh gave a global perspective of why end of life care is everybody's business primary palliative care. "The fate of anybody who is born is to die, we all need palliative care to be there for us whatever we die of," he said. Other speakers of the day included Dr. Izaq Odongo, the head of Oncology at the Ministry of Health who spoke about the current cancer situation in Kenya and Dr. Kibachio Joseph Mwangi, the head of the NCDC Unit at the Ministry of Health who noted that, "we want to move from a patient being passive to them being at the centre of care, from hospital focus to home care. Palliative care should go hand in hand with conventional care."

Delegates used various forms of dialogue and integration to share and benefit from different aspects of the conference. These included workshops, documentaries, first-hand accounts from care givers, presentations and reports and evening cocktails.

Prof. Scott Murray and Dr. Zipporah Ali brought the conference to an end with participants and conveners all looking forward to the next edition which will be held in 2016.

Palliative Care Conference



Health Cabinet Secretary Mr James Macharia officially opening the conference



Left to Right; Prof. A. Merriman - HAU, Dr. E. Luyirika - APCA, Mr. J. Macharia - MOH, Mr. P. Bunde - KEHPCA



Conference group photo - 18 -

Annex:

List of Palliative Care Providers

Free standing Hospices

1. Meru Hospice
2. Nairobi Hospice
3. Kisumu Hospice
4. Coast Hospice
5. Nyeri Hospice
6. Eldoret Hospice
7. Nyahururu Hospice
8. Nakuru Hospice
9. Thika Hospice
10. Embu-Mbeere Hospice
11. Kakamega Hospice
12. Murang'a Hospice
13. Siaya Roselyne Hospice
14. Laikipia Palliative Care Centre

Hospice and Palliative Care services in the Rural Community (FBO)

1. Kimbilio Hospice
2. VIAGENCO
3. Baraka Medical Centre - Nairobi
4. Our Lady Hospice Thigio
5. Shepherds of Life
6. KICOSHEP
7. FRACODEP

Hospices and Palliative Care Services in the Mission Hospitals

1. Our Lady Hospice Thigio: Limuru
2. AIC Litein Mission Hospital
3. PCEA Chogoria Hospital
4. Tenwek Mission Hospital
5. Maua Methodist Hospital
6. PCEA Kikuyu Hospital
7. Integrated AIDS (Assumption Sisters) Program - Thika
8. Nazareth Hospital

Teaching and Referral Hospitals

1. Kenyatta National Hospital
2. Moi Teaching and Referral Hospital

Government Hospitals with Palliative Care

1. Kakamega Provincial General Hospital
2. Coast Provincial General Hospital
3. Embu Provincial General Hospital
4. Nyeri Provincial General Hospital
5. Rift Valley Provincial General Hospital
6. Meru Level Five Hospital
7. Thika Level Five Hospital
8. Garissa Level Five Hospital
9. Kisii Level Five Hospital
10. Machakos Level Five Hospital
11. Busia General Hospital
12. Webuye District Hospital
13. Nanyuki District Hospital
14. Homabay District Hospital
15. Malindi Sub County Hospital

Private Hospitals with Palliative Care Units

1. MP Shah Hospital: Cancer Care Kenya
2. Aga Khan University Hospital Palliative Care Services

Annex: Map of Palliative Care Providers



Map of Palliative Care Providers



Annex:

KEHPCA Board Members



Mr Peter Bunde
- Chair



Stephen Gitonga
- Vice Chair



Faustin Mgendi
-Honorary Treasurer



Mrs. Roselyne Opindi
- Honorary Secretary



Dr. Brigid Sirengo
- Member



Saraphina Gichohi
- Member



Dr. Esther Munyoro
- Member



Dr. Meshack Liru
- Member



Mr Mohamud Jama
Madhar - Member

Annex:

KEHPCA team



Dr. Zipporah Ali -
Executive Director



Dr. Asaph Kinyanjui
-Director of Programs



Miriam Igobwa - Admin/
Finance Manager



David Musyoki - Senior
Program Officer



Dr. Esther Muinga -
Special Coordinator for
Access to Pain Relief and
Palliative Care



Josephine Muya -
Assistent Admin



Patrick Bowen -
IT Officer



Stephen Shiyuka -
Support Staff