

**2019 WORLD HOSPICE AND PALLIATIVE CARE DAY COMMEMORATION  
REPORT**

**DATE: 11/11/2019**

**VENUE: MWANZA COMMUNITY GROUND – MWANZA**



## **INTRODUCTION**

Palliative care is a family centered approach to provision of holistic care to both adults and children living with serious and life limiting illnesses such as: Cancer, chronic liver failure; drug –resistant tuberculosis and other chronic conditions. The main focus of care is relieving pain; preventing suffering and supporting the best possible quality of life and dignified death. The World Health Organization estimate that one percent of the total population, need palliative care. In Malawi; 175,000 people need palliative care according to Cumulatively 58 percent of the target population have been reached across the 94 palliative care sites available at all levels of care. In Malawi the event was commemorated on 11<sup>th</sup> November 2019 at Mwanza Community ground in Mwanza District.

## **THEME**

Every year the World Hospice and Palliative Care day is celebrated under a particular theme. This year's theme is **-Palliative Care: 'My Care. My Right'**. This theme focuses on lobbying policy makers to prioritize implementation of palliative care services as a comprehensive package of care within the national Universal Health Coverage; as well as lobbying government to ensure provision of holistic needs (physical, social, psychological & spiritual) to patients and families living with serious and life limiting illnesses. The 2019 theme; **Palliative Care: 'My Care. My Right'** is also empowering patients to demand access to Palliative Care as **a basic human right**; as well as empowering the general public to influence their policy makers to prioritize palliative care financing under Universal Health Coverage

## **AIMS OF WORLD HOSPICE AND PALLIATIVE CARE DAY COMMEMORATION**

The world hospice and palliative care day is commemorated with the following aims;

- share our collective vision to increase the availability of hospice and palliative care throughout the world by creating opportunities to speak out about these issues
- raise awareness and understanding of the needs – medical, social, practical, spiritual – of people living with a life limiting illness and their families
- raise funds to support and develop hospice and palliative care services around the world.

## **GUEST OF HONOUR**

In Malawi the WHPCD was presided by the Minister of Homeland and internal security Honorable Nicholas Dausi who is also a member of parliament for Mwanza Central on behalf of the Minister of Health and population Hon. Jappie Mhango.

Senior government officials from homeland and internal security, ministry of health were also present including the Secretary for health and population Dr. Charles Mwansambo Director of Nursing and midwifery services Mrs. Tulipoka Soko, district health officers, civil society leaders, and District executive members and also the private sector.

## **ACTIVITIES**

Activities to commemorate the day include: pavilions, drama, testimonies, traditional dances and speeches

During the event several activities were carried out and it started with a big walk by the guest of honor and other invited guest together with other people who were present displaying banners that had information relating to palliative care advocacy. The big walk started from Mwanza central market to community ground.



*Above picture shows the guest of honor Hon. Nicholas Dausi (Wearing a Hat) participating in the big walk.*

## **MINISTRY OF HEALTH**

This was followed by the display of galleries whereby palliative care providers had to showcase their activities in relation to provision of quality care for patients and their guardians. The Ministry of health had its display and was presented by Zenaida Phiri who said Malawi is making huge strides on issues of palliative care because it has a policy and guidelines which enhance the service delivery on palliative care. She said currently in Malawi palliative care services is provided at the central hospitals, district and rural hospitals including at community level. The Ministry is guiding implementation of the policy and guidelines and all activities

relating to palliative care

## **PACAM**

Palliative care Association of Malawi had had also to display its activities which was presented by the District support project Director Mr. Fred Chiputula who said the institution mainly focuses on advocating for improved palliative care services to those people whose voices cannot be heard or they are living in remote areas which includes development of palliative care policies and also mobilize resources aiming to support the ministry of health that palliative care services are in place and of good quality.

This is in line with the UHC, leaving no one behind. Development of IEC materials for palliative care such as human rights leaflets, guidelines for analgesic ladder is also another important activity to make sure that the information reaches out to many people in Malawi. He further said PACAM conducts Mentorship and supervision programs across the country whereby staff members go around the district hospitals with an aim of building the capacity of palliative care providers but also work with them hands on to show how quality palliative care can be provided holistically at primary, secondary and tertiary level.

His sentiments were echoed by the Executive Director for PACAM Mr. Lameck Thambo who further said palliative care services also require pain relief medication as Morphine for the management of moderate to severe pain. Through the Malawi Government Morphine is available in Malawi but there is limited access due to regulations and laws. The majority of the palliative care patients are available at the primary health care in rural areas but the concern is of restrictive laws because the pain relief medication can only be found at secondary level where we have district hospitals and also tertiary level where we have the referral central hospitals. He hinted the need to review the laws if the country is to achieve the Universal Health Coverage.

The Guest of honour also wanted to know how the association is responding to challenges affecting patients and guardians when the patient has been discharged from the hospital for continuum of care at home and also (Issues of psychosocial support), how is the association working with the government more especially the ministry of Health in following up of patients periodically at their homes to see their condition and in responding to that Fred said the association uses the WHO guidelines which says palliative care providers should be well trained and that the Ministry of health produced a palliative care home based model which was adopted by PACAM.

This means that there must be an assurance for those patients discharged from hospital that the care will still continue at home and they will be monitored by health workers in their respective places. This is why PACAM through the STEP UP project is supporting district hospitals in the central and Northern part of Malawi with Fuel for providers to conduct periodic home visits. The Home Based Care policy provides that people who are not trained should not provide health services without the knowledge of the ministry of health officials. There are HSAs, Community Nurses who are trained by PACAM through HBC groups.

Finally, Fred said failure to provide continuum of care by health officials at community level violates patients' rights to access to the services and good health which is in line with the 2019 WHPCD theme 'My Care, My Right'. Patients are empowered to demand their right to quality

care.



*Picture above shows part of display work of PACAM presented by Fred Chiputula*

## **NDIMOYO PALLIATIVE CARE**

The Ndimoyo Palliative Care, in Salima had also displayed and presented their work in support to Palliative care services in Malawi. The Clinical officer for Ndimoyo high lightened issue of home based care which they support to those palliative care patients who cannot manage to walk to the facility to receive treatment. The facility also trains palliative care providers in CHAM and government hospital in principles of palliative care in Chitipa to Nsanje so that there is quality of services in Palliative care. The Ndimoyo Palliative care is working hand in hand with the ministry of health and other partners such as PACAM to provide quality palliative care services starting from the primary level where the majority of patients are found.



*The pic above shows guest of honor appreciating the Ndimoyo Palliative care work*

## **MWANZA DISTRICT HOSPITAL**

The host district facility also displayed some of their work in relation to Palliative care delivery in order to improve the quality of life of patients and their families. This was presented by the District Palliative care coordinator who mentioned services such as home base care with an aim of following up patients for continuum of care and being able to give them good medicine. They have a stand-alone clinic and is run by nurses and clinicians trained in Palliative care. The clinic is run on a daily basis and patients receive counselling and proper medicines such as morphine for pain management.

The event was also spiced up with local dances, poems and drama with information relating to the theme which is to raise awareness on the lived experience of the people affected by the incurable or life limiting illnesses. It is also focusing on the financial impact of palliative care needs on individuals and households, including a human rights approach in access to care in a dignified manner.

## **TESTIMONIES**

Palliative care aims to improve quality of life for patients and families suffering from life

limiting illnesses. During the event clients gave their testimonies on how palliative care have helped them to improve their lives.

There was a male client who comes from Eliya Village TA Kanduku in Mwanza who said in 2006 he noticed that his leg kept on swollen with blister emerging. He visited the hospital several times to see what was wrong with his swollen leg and was asked by the health workers if he had ever gone for HIV Testing. Health workers recommended for HIV testing which the client accepted and after that he was diagnosed HIV Positive and cancer of the Skin. He said he was enrolled on Palliative care because he could not walk and for so long and he started receiving medication and now he sees great improvement because he is able to walk and people stopped stigmatizing him in a society as it was in the first place. He thanked Palliative care services for improving his life more especially on the care he received from the hospital in terms of counselling and treating the symptoms.

Another Client a child who came with her mother. The mother testified that her child was born a normal person but after 7 months she was sick and her skin was pale. She took her to hospital and it was discovered that she had little blood and blood transfusion was done then they went back home and after few days the illness continued and she went back to the hospital and it was the same problem and the third time she went was told by doctors that they cannot be continuing giving her blood and she was referred to laboratory for further tests. She was diagnosed with Sickle cell and she was counselled to monitor the child when she is growing up pain will be around her body and if she notices that should immediately go back to the hospital. After some months the girl was feeling pain and went the mother took her to the hospital she was enrolled on palliative care and was given morphine to manage the pain. pain management was done and the girl started going to school and was happy due to the services given at the palliative care clinic. She encourages other people who have relatives of such nature to go to the hospital to be assisted by trained palliative care providers and Doctors.

GJ is a female client of TA kanduku in Mwanza. She had swollen leg and was in pain and she went to the hospital where she was diagnosed with skin cancer and was enrolled on palliative care and was given pain relieves medications and other drugs to control the symptoms manage the pain. She is now feeling well because she is able now to walk alone because of the care she is getting at the palliative care clinic unlike the time she was just staying at home and trying different medicines and herbs without knowing that it was cancer. She encouraged other people who may notice strange things in their body such as swollen legs, wounds that fails to heal to go to the hospital to see the root cause of the problem before it comes to an advanced stage.

## **SPEECHES**

### **GUEST OF HONOR**

In his remarks the Guest of honor Hon. Nicholas Dausi said the event is celebrated on 12th October worldwide and as a country, Malawi is a signatory to various international norms and obligations He further said that palliative care entails that as a nation after patients are diagnosed with cancer for example or any disease which trouble the patients or life threatening illness, there comes a time when they are discharged from hospital and sent home for continuum of care and

they are looked after by family members or guardians.

The health personnel should continue making home visits to check how the patient is responding to medication and social issues at home as a matter of improving quality of life holistically. He said palliative care encourages the families including the patient to observe health regulations, advice and doctor's initiatives to see to it that there is care, the patient is having food and even pain relief and other essential medicine for palliative care. He also mentioned that palliative care is more of the heart, the passion and said patients should be treated with a smile and good heart and look at what the patients wants. He said in Malawi is the same that when people are sick they need to be given continuous medication and care until their condition improves and get back united with the family.

### **SECRETARY FOR HEALTH AND POPULATION (DR. CHARLES MWANSAMBO)**

He said in Malawi there are a number of individuals and organization doing a commendable job to make sure that any Malawian with life threatening condition should be free from pain and distress. He said Globally about 18 % have access to palliative care and in Malawi the percentage is at 57% which commendable despite the challenges that may come across.

Dr. Mwansambo mentioned the challenge of Human resource and that the health sector is not spared in shortage of human resource because there must be people who should be going to communities to follow up patients who have been discharged from hospital for continuum of care at home. He said the ministry is training more health workers to add the number who will be following up patients at their respective homes so that they don't travel long distances to access the services. Mobility in terms of transport such as a motorbike, push bike or even a vehicle was also mentioned so that health workers can ably travel to where the patients are residing.

On Morphine availability he said it is a controlled drug and that's why it cannot be found anywhere but only in district and central hospitals. He further said the government is making steps to take it closer to the people in rural areas either by taking the drugs to the people in rural by health workers or making the facilities closer to people in order to increase access.

### **PACAM EXECUTIVE DIRECTOR ( LAMECK THAMBO)**

He thanked the organizers for the event and said people in communities do associate chronic illness with witchcraft which was wrong hence the need of palliative care to come in and address those myths. This is most of the times why people are dying in the village because they are not able people are not able to care for the disease. Lameck further said palliative care comes in to help the family members to understand the need to caring the patient, to help the health care workers in hospitals the need for providing palliative care services in hospitals in order to improve the quality of life of patients in accordance with the theme My care, My right.

### **ATTENDANCE BY INSTITUTION**

	<b>NAME OF INSTITUTION</b>	<b>NUMBER OF PEOPLE ATTENDED</b>
1.	PARTINERS IN HEALTH	<b>5</b>
2	NDIMOYO PALLIATIVE CARE	<b>3</b>



3	CHIKWAWA DHO	5
4	MWANZA DHO	30
5	PCST	3
6	UNC	4
6	BLANTYRE DHO	2
7	MANGOCHI DHO	5
8	CADECOM MWANZA	1
9	ZOMBA DHO	2
10	DEDZA DHO	3
11	QECH	2
12	MEDICINES SAN FRONTIRES	2
13	MULANJE DHO	2
<b>14</b>	GUEST OF HONOR STAND	<b>36</b>
<b>15</b>	TENT 1	<b>52</b>
<b>16</b>	TENT 2	<b>46</b>
<b>17</b>	TENT 3	<b>12</b>
	<b>TOTALS</b>	<b>215</b>