

FARAJA HOSPICE AND PALLIATIVE CARE PROGRAMME

2016 REPORT



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## **1. ABBREVIATIONS AND ACRONYMS**

<b>ALMC</b>	<b>Arusha Lutheran Medical Centre</b>
<b>CBHC</b>	<b>Community Based Health Care</b>
<b>FCBHC</b>	<b>Faraja Centre CBHC</b>
<b>FHPCP</b>	<b>Faraja Hospice &amp; Palliative Care Programme</b>
<b>HBC</b>	<b>Home Based Care</b>
<b>IGA</b>	<b>Income Generating Activity</b>
<b>MMM</b>	<b>Medical Missionaries of Mary</b>
<b>MoU</b>	<b>Memorandum of Understanding</b>
<b>MOHSW</b>	<b>Ministry of Health and Social Welfare</b>
<b>OMS</b>	<b>Oral Morphine Solution</b>
<b>ORCI</b>	<b>Ocean Road Cancer Institute</b>
<b>PC</b>	<b>Palliative Care</b>
<b>PLHA</b>	<b>People Living With HIV/AIDS</b>
<b>TFDA</b>	<b>Tanzania Food and Drug Authority</b>
<b>SRRH</b>	<b>Singida Regional Referral Hospital</b>
<b>VCT</b>	<b>Voluntary Counselling and Testing</b>

## **1. PALLIATIVE CARE REPORT 2016**

The Faraja Centre Hospice & Palliative Care (PC) Programme was started in August 2012 after a Needs Assessment showed that people suffering from terminal illnesses in Singida Municipality had no access to treatment that they needed, especially pain control. This Programme is part of Faraja Centre CBHC which was started in 2005 in Singida, Tanzania, East Africa to provide various services related to HIV/AIDS. Faraja provides Voluntary Counselling and Testing (VCT) to people wanting to know if they have HIV; Awareness Raising in schools and villages about HIV/AIDS, malaria and malnutrition; Income Generating Activities (IGAs) for those with HIV/AIDS; School Fees for Orphans and Vulnerable Children and a large Home Based Care (HBC) Programme for People Living with HIV/AIDS (PLHA). It is owned and administered by the Medical Missionaries of Mary, an international Congregation of Catholic Sisters, under the Roman Catholic Diocese of Singida.

## **2. AIM OF THE PROGRAMME:**

To provide Hospice & Palliative Care (PC) to those with terminal and chronic diseases in Singida Municipality which embraces nineteen (19) Wards and includes Singida town and has a population of approximately 150,379.

### **Key Actions**

- To provide a holistic Palliative Care service which embraces the physical, psychological, spiritual and social needs of those served
- To identify patients needing Palliative and especially Hospice Care
- To provide Home Based Hospice and Palliative Care to these people with a skilled Team which is capable of using oral morphine and other Palliative Care medications where they are needed.
- To educate and support the family members and other carers of those receiving PC services

- To educate the larger community starting with local government and religious leaders about chronic diseases, especially cancer, what can be done to treat them, how family members can be involved and especially how to obtain quality and appropriate End of Life Care.
- Inform political leaders of this service in the Municipality and obtain their support both moral and financial.

### **3. WHAT HAS BEEN ACCOMPLISHED FROM 1 JANUARY THROUGH 31 DECEMBER 2016**

- i. At the beginning of 2016 Faraja Hospice and Palliative Care Programme had three staff and a part-time driver:
  - a. Sr. Dr. Marian Scena, MMM, Programme Coordinator,
  - b. Mrs. Amina Kimashalo, PC Nurse and Supervisor of Volunteers,
  - c. Mrs. Matilda Saul, PC Nurse, and
  - d. Mr. Shabani Miloho, driver.
- ii. The Memorandum of Understanding (MOU) with the Regional Referral Hospital, Singida regarding the storage and dispensing of oral morphine is still in effect. The Faraja Doctor writes the prescriptions and one of the Team collects the morphine as needed. An Oral Morphine Licence, from the Tanzania Food and Drug Authority (TFDA), was received by SRRH in October 2013 and morphine became available for us. This MOU was made in August 2012 and updated in January 2013. We are very grateful to Singida Regional Referral Hospital for the MOU and for the cooperation we receive, especially from Dr. Bariki Misholi, Head of the Hospital Palliative Care Team. We are very grateful that there was no shortage of oral morphine in 2016.
- iii. **Official Registration of FHPCP by the MOHSW was received on 6 September 2013.** It is renewed yearly, but this year Faraja is pursuing a Registration that will include all Departments and services of Faraja CBHC.
- iv. Hospice and PC patients are visited Monday, Wednesday and Friday of each week with occasional emergency visits. The frequency of visits to a patient depends on that patient's condition and needs and/or the needs of the carers.

- v. We have found that education of and support to the carers of our PC patients is almost as important as the care of the patient! Many are caring for patients at home, most often without electricity or running water. This complicates the provision of good care and increases the workload of the carers. We demonstrate how to care for the patient and encourage them in their service. On several occasions we discovered that the Carer had severe medical problems because of the stress of caring for the patient!
- vi. Faraja PC Programme receives patients through referrals from: local government leaders, religious leaders, Ocean Road Cancer Institute (ORCI), Dar es Salaam; hospitals and dispensaries, our own PC Volunteers, the TUNAJALI HBC Volunteers and by word of mouth.
- vii. The office of the local Minister of Parliament was not visited 2016. We need to make this contact in 2017.

PALLIATIVE CARE VOLUNTEERS. A two weeks PC Volunteer Training Course, officially recognized by the MOHSW, was conducted from 25 November through 6 December 2013 at Faraja Centre. Our Volunteers are 8 women and 6 men. They were chosen from 10 out of the then 16 Wards of Singida Municipality. Each PC Volunteer, upon completion of the course, signed a Contract that is renewed yearly, and received a bicycle, raincoat and PC Kit with basic supplies to be used by them. In their Contract with Faraja Centre they have agreed: to spend at least 12 hours every month visiting their patients and looking for new ones, to keep records of the patients they visit, to attend the monthly Volunteers Meeting at Faraja Centre and to receive a stipend of TZS 30,000 per month.

Their work includes:

- To look for people in their community who need Palliative Care
- To visit their patients and keep records of each patient visited
- To report to the PC Team those patients needing to be visited by the PC Doctor and Nurses

- To visit the community and give health education, especially about Palliative Care

Since 1 January 2016 until 31 December 2016, the PC Volunteers brought a total of 29 patients (9 males and 11 females) who have been accepted into the PC Programme. The PC Team has brought 26 (10 males and 16 females) into the Programme. The total is 46 of which males are 19 and females 27.

The PC Volunteers Supervisor is Nurse Amina Kimashalo. Her work includes:

- Supervision of the PC Volunteers
- To supervise the Volunteers Monthly Meeting
  - Receive the Volunteers Reports and collate them in a report for the Municipal Home Based Care Supervisor
  - To keep the Volunteer Master Register
  - To receive statistics from the PC Volunteers

Other work of the PC Nurses includes:

- To write up a Summary of Patient Visits
- To keep the Pharmacy Register
- To keep a Register of the use of Morphine (DDA Book)
- To keep a Patients Register
- To register new patients

#### **viii. CAPACITY BUILDING**

The Volunteers Monthly Meetings are used to build Capacity. Some months there are inputs on useful topics; the Meetings provide a forum where questions can be asked and difficulties encountered are discussed for the benefit of all. This year the PC Team presented “The Stages of Grief” which was followed by a lively discussion. Periodically “The Making of a Will” and its importance is discussed so that the Volunteers can help their patients make a Will.

Staff Matilda Saul attended the 5<sup>th</sup> International African Palliative Care Conference in Kampala, Uganda from 16-19 August 2016. On 29 October Matilda returned to Uganda for a week of practical experience at Hospice Africa Uganda (HAU), 3 weeks experience in Mobile Hospice Mbarara (MHM), and a 5 day Health Professionals Course at HAU. Her experiences are being integrated into our Programme.

**ix. STATISTICS 2015**

<b>GROUP</b>	<b>MALE</b>	<b>FEMALE</b>	<b>TOTAL</b>
Patients accepted into the Programme	19	27	<b>46</b>
Patients not accepted into the Programme	3	10	<b>13</b>
Patients accepted before 2015	30	31	<b>61</b>
Those who moved or were discharged	2	1	<b>3</b>
Visits:			
By the PC Team			<b>928</b>
By the PC Volunteers			<b>1510</b>
Total			<b>2438</b>
Those treated with morphine	7	7	<b>14</b>
Deaths	20	18	<b>38</b>
Bereavement Visits	13	16	<b>29</b>

**x. THE THIRD REMEMBRANCE SERVICE FOR THE DECEASED OF THE FARAJA HOSPICE AND PALLIATIVE CARE PROGRAMME**

In 2014 Faraja Hospice and Palliative Care Programme saw the need for a Remembrance Service to commemorate all of our patients who had died since the Programme began in September 2012. From 2012-14 there were 60. We wanted to be sensitive to the local culture and the various religions of our patients. More than 50% of our patients are Muslim and they have different beliefs and customs from the Christians. And the various Christian denominations have differing customs too. None of the families in our local situation had had any experience of an ecumenical Remembrance Service like we had planned. So to cater to the various religions and cultures we decided to call the gathering a “Meeting to Remember our Deceased Patients in the Faraja Hospice and Palliative Care Programme”. Faraja Centre also has a large Home Based Care Programme for Persons Living With HIV/AIDS. Some of this Programme’s clients had died so the HBC Volunteers and the families of their deceased were also invited to attend the Remembrance Service. In 2016 the Third Remembrance Service was held on 17 November 2016 in Faraja Centre. We had a total of 47 deceased from November 2015 through November 2016: 38 from the Hospice and Palliative Care Programme and 9 from the TUNAJALI HBC Programme.

Those invited included: Faraja Centre staff, Faraja Hospice and Palliative Care Volunteers, TUNAJALI HBC Volunteers who had cared for some of the deceased, two persons from the family of each deceased, a Muslim religious leader or Shehe, whose deceased wife had been our patient in 2013, and a Catholic priest.



The Service was opened by the Faraja Hospice Coordinator who welcomed all present and explained that the purpose of the meeting was to remember all our patients who had died since November 2015. She hoped that, by coming together to remember our deceased and, perhaps, speaking about them and praying for them, that healing of the personal loss of our beloved might be promoted.

Unfortunately the Muslim religious leader was unable to attend at the last moment. So Father Bernard Ngalya, the Diocesan Health Secretary for Singida Catholic Diocese opened the meeting with a prayer.



Picture of PC Nurses and driver at the 3<sup>rd</sup> Remembrance Service, November 2016

This was followed by a “Reflective Naming of each Deceased”. There were 38 PC and 9 HBC deceased patients giving a total of 47. Each PC Volunteer or HBC Volunteer who had accompanied the patients and their families until and after death named each of the deceased they had accompanied. Then there was a short period in which families and Volunteers were encouraged to make short prayers for the deceased or to relate something they remembered

from the life of the deceased. After this Fr. Ngalya summed up the prayers and petitions in a final prayer.

The staff, Volunteers and family members were then invited for refreshments of soda and biscuits. More sharing took place in a more informal setting. When the PC Team discussed the Service with the families, staff and Volunteers during the refreshments period the families attending asked that a Service be held every year for those who had died because it had comforted and brought healing to them. The Volunteers had similar comments. Our PC Team felt that the Service had praised God, asked for mercy for our deceased, built bridges between the various religions and had provided a safe environment where sharing and further healing could take place. We will continue to have a Remembrance Service every year to remember our deceased patients and their families!

#### **4. IMPACT OF THE PROGRAMME.**

- i. The Catholic Diocese of Singida and Singida Municipality now have a functioning, high quality PC Team which provides Home-based Hospice and PC with medical, psychological, spiritual and social care to the people of Singida Municipality. The Team includes: a Doctor, 2 PC Nurses, a Driver and 14 PC Volunteers.
  
- ii. The Faraja Hospice and Palliative Care Programme has access to and is using oral morphine for the alleviation of pain in those needing it. In 2016 14 patients were treated with morphine. Thank God, there was no time this year that we failed to provide oral morphine for those needing it.
  
- iii. In 2016 46 patients were accepted into our Programme, 19 males and 27 females. Out of these 62 patients were brought by the PC Volunteers. Thirteen patients, 3 males and 10 females were assessed but not accepted because they did not fit the criteria for Hospice or Palliative Care. Our patients were aged 1-97 years. The Team made 928 visits in 2016 to patients ranging from 1 to 81 visits to a patient before death occurred or the year ended. The PC Volunteers made a total of 1510 visits giving a grand total of 2438 visits to patients.

v. **DIAGNOSES OF PATIENTS IN FARAJA HOSPICE AND  
PALLIATIVE CARE PROGRAMME.**

**MEDICAL CONDITIONS OF THE PATIENTS 2016**

NO.	CONDITION	M	F	Total	DEATHS		
					M	F	Total
1.	HIV/AIDS	4	11	<b>15</b>	2	4	<b>6</b>
2.	Cardiovascular condition	14	17	<b>31</b>	5	4	<b>9</b>
3.	Tuberculosis and HIV	0	2	<b>2</b>	0	2	<b>2</b>
	And not HIV	0	0	<b>0</b>	0	0	<b>0</b>
	<b>Total TB</b>	<b>0</b>	<b>2</b>	<b>2</b>	0	2	<b>2</b>
4.	Cancer and HIV+	1	3	<b>4</b>	0	3	<b>3</b>
	Cancer and not HIV+	13	14	<b>27</b>	9	4	<b>13</b>
	Total Cancers	14	17	<b>31</b>	<b>9</b>	<b>7</b>	<b>16</b>
5.	Paraplegia	1	2	<b>3</b>	0	0	<b>0</b>
6.	Neurological conditions	4	2	<b>6</b>	0	0	<b>0</b>
7.	Fracture	1	2	<b>3</b>	1	1	<b>2</b>
8.	Dementia	0	0	<b>0</b>	0	0	<b>0</b>
9.	Epilepsy	8	8	<b>16</b>	1	0	<b>1</b>
10.	Liver Diseases	2	1	<b>3</b>	0	0	<b>0</b>
11.	Renal conditions	0	0	<b>0</b>	0	0	<b>0</b>
12.	Diabetes/Complications	3	3	<b>6</b>	1	0	<b>1</b>
13.	Other conditions	4	3	<b>7</b>	1	0	<b>1</b>
	<b>TOTAL</b>	<b>55</b>	<b>68</b>	<b>123</b>	<b>20</b>	<b>18</b>	<b>38</b>

It can be seen from the above table that cancer and cardiovascular diseases are the most common diagnoses needing hospice or palliative care.

The epileptics are 11 children and 5 adults with an unreliable source of medication. Since using medication the occurrence of seizures has decreased dramatically.

## **5. FARAJA HOSPICE AND PC EXPENDITURE 2015**

Porticus Amsterdam CV provided funding for the “Setting Up of Faraja Hospice and Palliative Care Programme” from its beginning in Sept 2012 until August 2014. Parts of the Programme have been funded by Misesan Cara, Ireland; The Roundfort Group, Mayo, Ireland; donations through the Medical Missionaries of Mary, especially the Congregational Leadership Team; and family and friends of the Palliative Care Team. At present the Programme is funded by donors outside of Tanzania apart from morphine, which is provided without cost by Tanzania.

**In 2016 Expenditure for the Programme was**

**TZS 34,433,616.00 or Euro 14,971.14 / US\$ 16,396.96.**

## **6. CHALLENGES**

- i. Some useless or harmful local treatments, beliefs and practices.
- ii. Patients not realizing the importance of their treatment and stopping their treatment without informing the PC Team or Volunteers.
- iii. Poor communication from the patient and the family, for example:
  - To bring a patient to the home village without informing the PC Team
  - To move house without informing the PC Team
- iv. Some patients aren't open about their illness or the treatment they are using, for example they are using some medicines secretly and don't inform the hospital staff if they are admitted; or they decide to admit themselves to hospital without informing the PC Team.
- v. Many of our patients have potentially curable conditions but they present too late to be cured. There is a great need in Tanzania for Health Education especially about cancer and cardiovascular diseases.
- vi. We have no Volunteers in 9 of the Wards in Singida Municipality nor any outside of the Municipality and people there also need Palliative Care.
- vii. Several of the Volunteers were not visiting patients but reported that they were visiting. We have instituted a “Visits Book” which is given to each patient. When the Volunteer visits s/he records this in the book and the PC Team checks this book at each visit. This procedure is proving helpful.

## **7. PC STORY OF “Njiku”**

On 4 February 2016 our PC Volunteer SAN arrived with a man who he thought needed PC. SAN had gone to his shamba(farm) in a rural part of another District about 40km from Singida. There he met Njiku (not his real name) who was complaining of severe pain in his left chest and shoulder and not being able to sleep due to the pain. He also had a mass and large wound on his left chest. On questioning he had had an amputation of the end of his index finger in 2011. No pathology was checked. He was well until February 2015 when he noticed a mass in his left armpit. He went to another hospital and the swelling was biopsied and showed metastatic malignant melanoma, a type of skin cancer which had resulted from the problem in his little finger in 2011. There was no possibility of him going to the cancer hospital in Dar es Salaam. So we needed to treat his severe pain and the large ulcer or sore he had on his chest. We got oral morphine and gave it to him and he experienced great relief after 15 minutes. Njiku was married with 5 children and he had a small farm, but wasn't able to work on it due to his pain.

Usually our patients come from Singida Municipality but, on occasion, if a patient or a relative can come for the medications we agree to accept them into our Programme especially if they have severe pain and need morphine. We started to treat Njiku's pain following the “WHO 3-step Ladder” for pain control but he needed morphine to get relief of his pain. His relief of pain was so complete that he was even able to go to his shamba to work for a short time each day! Njiku was able to come to Faraja Centre to collect his morphine and our PC Volunteer visited him at his home in the village and even accompanied him on the bus to Singida when he needed more medications. We continued to treat Njiku from a distance and phoned his neighbour (the patient didn't have a phone) to assess his condition. On 21 May 2016 we received word that Njiku had died during the night. We were very happy that, although it wasn't easy to treat him at a distance, we had greatly improved his quality of life and he felt cared for by our PC Team.

## **8. ACKNOWLEDGMENTS.**

We are very grateful to:

- The Congregational Leadership Team of the Medical Missionaries of Maryfor encouraging us to start the PC Programme and for directing a large donation to the Programme in 2014
- The Director and Staff of Faraja Centre CBHC for their interest, support and close collaboration

- The new Bishop of the Roman Catholic Diocese of Singida, Bishop Edward Mapunda, and the Diocesan Health Secretary, Fr. Bernard Ngalya, for their support and interest.
- The MOHSW for Registration of the PC Programme
- The Regional Medical Officer, Singida and Municipal Medical Officer, Singida Municipality for their interest and encouragement
- The Medical Officer in Charge of Singida Regional Referral Hospital for entering into a Memorandum of Understanding with Faraja Hospice and Palliative Care Programme for the procurement of oral morphine and for use of their laboratory facilities and for good support and cooperation.
- Our benefactors who have made this Programme, possible through their donations:
  - Porticus Amsterdam CV;
  - Roundfort Group, Mayo, Ireland;
  - Congregational Leadership Team of the Medical Missionaries of Mary,
  - CED (Christlicher Entwicklungsdienst) Germany for providing essential medications for our patients, and
  - family and friends of the Palliative Care Team and the Medical Missionaries of Mary.

**Without them we would have no Programme!**

Submitted by:

*Sr. Marian Scena, M.M.M.*

Sr. Dr. Marian Scena, MMM,  
Coordinator  
Faraja Hospice and Palliative Care Programme