



Our Lady's Hospice – Lusaka, Zambia

Sister Ann Kelly and colleagues work in Our Lady's Hospice, Lusaka, Zambia. Theresa Park, one of our parishioners, is Sister Ann Kelly's sister.

Please read on to discover more about the work of Sister Ann Kelly and colleagues and their work in Our Lady's Hospice, Lusaka, Zambia

BACKGROUND

Our Lady's Hospice is a Faith-Based Organization situated in Kalingalinga, Lusaka, Zambia. Four Catholic Religious Congregations are involved in the administration of Our Lady's Hospice; Franciscan Missionaries of the Divine Motherhood (FMDM), Oblates of Mary Immaculate (OMI), the Dominican Sisters (OP), and St. Patrick's Missionary Society (SPS also known as Kiltegan Fathers). The Hospice is under the patronage of His Grace the Archbishop of Lusaka. It is a registered charity under the Companies Act of Zambia that has the support of the Zambian Ministry of Health as well as that of medical experts from the University Teaching Hospital and some committed lay professionals that include those from religious orders.

Our Lady's Hospice depends on charity and generosity to be able to function. Here at Saint Joseph's Epsom we support this very worthy cause and have included it in our parish family mission – Saint Joseph's Epsom: Faith in Action.

MISSION

The mission of Our Lady's Hospice is to promote and provide quality Palliative Care through a committed team in a conducive environment for patients who have HIV and AIDS, and Cancer. Through faith, patients suffering from a life-threatening illness are helped to come to terms with their illness and to renew hope for living with a certain quality of life until death.

Palliative Care as defined by the World Health Organisation (WHO 2002) is, 'An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'.

In accordance with this definition the aim of the Hospice is to enhance the quality of life of people living with HIV and AIDS (PLHAs) and others with life-threatening illnesses, by controlling their pain and giving them the courage to live as full a life as possible throughout their illness and to enable them to die in peace and dignity when the time comes. This holistic approach to care offers physical, psychological, social and spiritual care to patients. Being a Faith-Based Organization, spiritual care is a very important component of the program and faith motivates all the services. Spiritual care offers patients hope in what can often be hopeless situations, encouraging them to accept their situation and to live in peace with that acceptance.



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At Our Lady's Hospice patients of all faiths are welcomed, without discrimination. Any patient who is in need is never turned away, day or night. The services at the Hospice are available at minimum cost to all who need palliative care. However, those who cannot afford to pay are given priority.

ORIGINS

The idea of setting up a hospice came about as an answer to the tremendous need of the terminally ill in a growing HIV and AIDS pandemic in Zambia. In the early days of this pandemic, the formal government health system could not respond adequately to the huge burden of care, the number of patients and above all the high death rate. In such a scenario, patients were discharged from hospitals because there was no solution and nothing more could be done for them; beds in hospitals were required for acute cases. Patients were discharged from hospital in a weak state and some even died in an undignified manner. The Franciscan Missionaries of the Divine Motherhood felt the need to respond to this overwhelming need and in conjunction with three other religious congregations, funds were sought to begin the process of building a hospice.



CHALLENGES OF HIV / AIDS



Traditionally Hospice care was associated with care of the dying and for this reason many shy away from palliative care. However, in the era of Antiretroviral Treatment (ART), the role of Hospice has changed in line with the definition of palliative care to an approach of care offering an improved quality of life for all suffering from life-threatening illnesses such as HIV and AIDS, and Cancer. Our Lady's Hospice helps people to understand what palliative care is and aims to provide quality care to those who need it. There are a number of factors contributing towards the inability of households to adequately care for their chronically sick that influence the services provided at Our Lady's.



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- Many poor people can't afford the cost of user charges for health services.
- The HIV and AIDS pandemic is already absorbing a large share of hospital resources. HIV and AIDS related illnesses account for about 70% of all hospital admissions in Zambia according to the Ministry of Health (MOH).
- The ability to provide adequate care at home is extremely limited in many families because of the lack of surviving family relatives as well as the prevailing poverty that is being experienced.

THE PRESENT SITUATION

Currently Our Lady's Hospice is serving the community in Kalingalinga and the surrounding catchment area with a population of approximately 250,000. It is estimated that in such a cohort of people at least 50,000 may be infected with HIV. Each month, the Hospice caters for an average of 60 in-patients and 1,600 out-patients. In recent years the role of the Hospice has changed from only end-of-life care, to offering a more comprehensive holistic approach to palliative care that includes ART and pediatric care. However, the Hospice still caters for patients at the end-of-life stage of their illness with the facility to admit up to 33 in-patients in 5 different wards/houses.

Currently the Hospice is registering on average about 20 deaths per month. High rates of morbidity and mortality in patients with HIV and AIDS are due largely to opportunistic infections related to immune-suppression. These conditions, with proper diagnosis and management can be treated, life expectancy can be increased and the quality of life enhanced. The types of infection managed presently at the hospice level include:

- Pheumocystis cariini pneumonia
- Diarrohea diseases
- Toxoplasmosis
- Mycobacterial disease
- Cryptosporidial
- Crypto meningitis
- Tuberculosis
- Pneumonia
- Cancers (kaposi sarcoma, lymphoma, prostate, breast & cervical cancers)
- Malaria
- Anaemia
- Hepatitis

As well as the manifestation of clinical symptoms many of the patients suffer from depression and are anxious, needing time to talk to and be listened to. In addition, there are numerous cultural difficulties around the subjects of death and dying. Our Lady's Hospice with its multi-disciplinary approach offers a package of palliative care that has proven to be successful. Many patients get well and go home to their work and families, while others, especially those who were late in accessing treatment or those who defaulted from treatment, don't do so well. But through the palliative care approach the end of life can be peaceful, largely free of pain and dignified.



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Most of the clients at Our Lady's Hospice are faced with the task of maintaining optimal nutritional status and of overcoming the progression to full blown AIDS through good and adequate nutrition. The Hospice provides proactive nutritional interventions such as High Energy Protein Supplement (HEPS) and Ready to Use Therapeutic Food (RUTF) both to in-patients and out-patients when such resources are available. A kitchen garden at the Hospice provides a daily supply of fresh green vegetables. The Hospice endeavours to provide a healthy and balanced diet for its patients and to advise on this after discharge, believing that such an approach will delay the progression of HIV, reduce the cost of medical care, reduce complications and hospitalizations, shorten the duration of hospital stays, improves the effectiveness of and tolerance to medications and treatments, increases independence and the ability to stay at home.

The aspect of respite care for the terminally ill involves the concept of Hospice as a place of rest. By this is meant that the Hospice offers a period of time where the primary caregiver in the home gets a break from the strain of caring for a patient with all the demands that such care requires. As well as allowing the primary caregiver some free time to attend to personal business, the patient also benefits with the chance for more intensive and specialized care.

STAFFING

Our Lady's Hospice has the following staff:

Clinical Officers	2
Nurses	6
Physiotherapists	1
Pharmacists	1
Counsellors	3
Caregivers	24
Spiritual directors	1
Maintenance	7
Drivers	1
Security officers	4
Caterers	5
Administration officers	4
Reception/Data/Filing	5
Pastoral caregivers (part-time)	1
Doctors (part-time)	2
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All of the above, except those who are part-time receive salaries for full-time work at the Hospice. None of the salaries come from the Government but all have to be sourced from elsewhere. Recent years saw a pruning of personnel in order to make ends meet while still trying to offer quality service to all clients, both day and night.



FACILITIES AVAILABLE AT THE HOSPICE

In the provision of quality palliative care, Our Lady's Hospice offers the following facilities:

- Training Centre
- Out-Patients Department
- In-Patients Wards/Houses
- ART Clinic
- Counselling Department
- Paediatric Clinic
- Chapel/Chaplaincy Unit
- Physiotherapy Department

Training Centre



The training centre prioritizes the training of primary caregivers, in particular the family members of the sick. Most of the patients are from resource-limited environments living in poor socio-economic conditions. Health care is often neglected and therefore it is vital to train the family members in the provision of basic care for their loved ones who are suffering from life-threatening illnesses. The best care for the terminally sick can

be given by those relatives who care for them in their own homes. Training is also offered on a regular and on-going basis to members of staff in addition to their initial formation as caregivers. Youth workshops are provided at the Hospice for pupils from local schools. These workshops teach youth how to prevent the spread of HIV, how to be responsible in the fight against AIDS and how to look after family members suffering from the disease.

Out-Patient Department

Fortunately many patients do not need in-patient care. Therefore, the out-patient department has a major role to play in the provision of palliative care. Our Lady's Hospice caters for HIV patients who are mobile and in need of ART and treatment for various opportunistic infections such as TB, skin disorders etc. These patients are monitored carefully and are provided with psycho-social and spiritual counselling. The out-patient department works on a triage basis. Since it has a wide catchment area, it is able to reach a large number of people in need of quality



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palliative care services. In addition, patients are encouraged to join a support group where, in an atmosphere of care and trust, they learn to support one another. Practical exchanges concerning the taking of medication, side effects of drugs and the adopting of a suitable lifestyle help the members to adhere more faithfully to the drug regimen and to changes that may be required if one is to remain healthy.

In-Patient Houses/Wards



There are currently 4 in-patients' houses/wards, although the original plan was for the building of 12. Each house caters for 6 patients. These houses became operational in August 2003. In addition there is a special-care unit that helps to stabilise critically ill patients who arrive at the Hospice in a very serious condition. Intensive care is given until the patient stabilizes or recovers. Those who recover are transferred to other wards or discharged home. In total the Hospice caters for up to 33 in-patients.

ART Clinic

Antiretroviral Treatment which is now available free of charge to HIV positive patients has been welcomed most especially by the poor, who up to this time could never have hoped for such an opportunity to prolong their lives and to have a better quality of life throughout their illness. Drugs are available at the Hospice and are presently being administered on a three-monthly cycle. Adherence support is given to these patients in order to help them follow their medication regimes. A total of over 4,700 out-patients have been attended to since the clinic began its operations. Of these almost 3,000 have been put on ART.

Counselling Department

Patients coming to the Hospice are offered Voluntary Counselling and Testing (VCT) with same-day results. When it has been established that the patient is HIV positive, the patient undergoes further tests to determine their eligibility for ART. If proven necessary they are then enrolled on the ART programme.

Chapel/Chaplaincy Unit

While at present the Hospice does not have a physical building for a chapel it has been able to provide a wide and varied programme in spirituality. This service was spearheaded through the services of a full-time chaplain. Spiritual counseling was offered to in-patients on a regular basis and as required. Spiritual services such as



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Mass and other prayer services were organized especially for particular events such as Christmas and Easter. In addition the Hospice was used as part of the pastoral training programme for those in formation for religious congregations. These young people



were introduced to the care of the sick and the dying from the perspective of spiritual and pastoral care. A part-time pastoral caregiver visits the patients on a regular basis, offering them and their families comfort and support and well as encouraging the staff who care for the sick. Other denominations/faiths are welcome at the Hospice and patients have regular visits from visiting ministers from other churches. These ensure that the spiritual needs of patients and their families are fully met and provided.

Physiotherapy Department



The physiotherapy unit offers a daily service to to patients in need of rehabilitation and especially to ART patients who suffer from neuropathy. The physiotherapist assesses, diagnoses and prescribes treatment for diseases and injuries. Exercise, massage, ergonomics, electro, hydro, ice and manual therapy are used in the treatment as required. Complicated cases are referred to other health institutions for further management, where necessary. In some cases investigations to help with diagnosis, treatment and prognosis may need to be ordered.

Paediatric Clinic



Our Lady's Hospice recognizes the need to include children in care and especially those suffering from HIV and AIDS. At Our Lady's Hospice quality paediatric palliative care is provided through a weekly children's clinic. Currently almost 300 children are registered on the program with up to 50% of these started on ART. Adherence support is offered in the same way as to adults but all paediatric services are provided in a child-friendly environment and manner.

LINKAGES

Our Lady's Hospice has from its inception worked closely with other players in the HIV and AIDS field. These now include the following:

- University Teaching Hospital, Lusaka (UTH)



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- Lusaka Urban District Health Management Team (LUDHMT)
- Palliative Care Association of Zambia (PCAZ)
- Cancer Hospital, Lusaka
- Kalingalinga Health Centre, (TB Unit, Laboratory, Mortuary)
- Home Based Care Programmes, Lusaka (HBC)

The Hospice has also been a key player in implementing programmes such as:

- 'Success' programme under the Presidents Emergency Fund for AIDS Relief (PEPFAR) through Catholic Relief Services (CRS)
- ART adherence/compliance programme under Centre for Infectious Research in Zambia (CIDRZ)

The Hospice is used as a recognised placement centre for students from:

- University of Zambia
- Kara Counselling
- Chainama College
- Evelyn Hone College

CHALLENGES

The following are among the main challenges faced by Our Lady's Hospice:

- Sustainability
 - ✚ The need to hold fund-raising events
 - ✚ The need to develop a high cost unit for in-patients
 - ✚ The need to rent the training centre facilities to interested groups
 - ✚ The need to rent the gym facilities to interested groups
 - ✚ The need to cultivate a vegetable garden
 - ✚ The need to develop self reliance among the staff (Savings and Loan Association)
- Accessibility
 - ✚ The need to be on a public bus route
 - ✚ The need to have a vehicle/driver to help in transporting patients
- Electricity
 - ✚ The need to run oxygen machines
 - ✚ The need to resuscitate patients
 - ✚ The need to keep bodies cool before transfer to mortuary
 - ✚ The need to cook meals
- Personnel
 - ✚ The need for staff, in particular junior members, to be seconded to the Ministry of Health and under the Government payroll
 - ✚ The need for anti-malaria and anti-TB treatment to be made available from the Ministry of Health
 - ✚ The need for recruitment of specific staff in order to qualify for full accreditation as a medical institution
- Resources



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- ✚ The need to maintain a viable ART out-patient centre when CIDRZ withdraws in February 2010
- ✚ The need to continue with the present level of in-patient care when CRS withdraws in December 2009
- ✚ The need to procure laboratory and x-ray equipment for carrying out tests requested by clinical specialists in their day-to-day diagnostic procedures
- Treatment
 - ✚ The need to have morphine treatment for patients in terminal care
 - ✚ The need to develop further pain management skills and symptom control mechanisms
 - ✚ The need to have more people trained in palliative care within Zambia
 - ✚ The need to address socioeconomic issues such as poverty, employment, nutrition and income

