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Abstract

The Pretoria Sungardens Hospice, South Africa was the beautiful location of my summer project. Saunders and Sykes (1993) define a Hospice as “a centre that would specialize in pain and symptom control in the terminal stages of disease but also provide an environment that would allow people to adjust emotionally and spiritually to their approaching death”. The Sungardens Hospice seems to fill these criteria perfectly.

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Palliative Care Experiences in the Pretoria Sungardens Hospice, South Africa.

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The Pretoria Sungardens Hospice, South Africa was the beautiful location of my summer project. Saunders and Sykes (1993) define a Hospice as "a centre that would specialize in pain and symptom control in the terminal stages of disease but also provide an environment that would allow people to adjust emotionally and spiritually to their approaching death". The Sungardens Hospice seems to fill these criteria perfectly.

Set up in 1987, the hospice was originally a mobile unit providing palliative care in the community of Pretoria. Eventually an old convent building was offered for use as a ward before the E.G. Chapman Group donated the area of land the Hospice now occupies. Since then, as a result of hard fundraising, the Hospice staff have accumulated enough money to build a stunning complex from where they now plan to carry out their valuable work.

Situated in a tranquil garden, the hospice consists of a main building, an In-Patient Unit, a Chapel and a newly built block with shops and a library. It is from these small shops that the hospice earns its main income, around R140,000 a month, an amazing total considering that these shops are stocked chiefly by public donations.

It must be noted that the hospice services are provided free of charge for those who are unable to pay for this specialized care. Therefore, for the Hospice to continue successfully, they rely on donations of money from the public and patients' families. The sheer generosity of people and the ongoing determination of the staff to succeed amazed me.

In addition to the main hospice in Pretoria are two satellite hospices in the surrounding townships of Mamelodi and Atteridgeville. However, patient care is not restricted to the set hospice buildings. The majority of care takes place in the community with qualified nurses visiting and treating patients in their homes. When home care becomes too much for the patient and their family to cope with, admittance to the IPU in Pretoria allows for a period of respite or can provide a safe and comfortable environment for the person to die at peace, an event which is sadly often the case.

Day centres allow time for some patients to get out of their homes and enjoy the company of others, providing them with some degree of emotional support and companionship. In the townships and squatter camps the importance of the day centres to the patients is enormous. Not only are they socialising and receiving care, they are provided with clothing and two well balanced meals a day, basic needs taken for granted by those in better off circumstances.

The hospice works with three doctors who provide their services in the IPU as additional work to their normal responsibilities. A referral system is maintained by networking with the Hospitals, Clinics, Traditional Healers "Bossiedokters" (Bush doctors), Support Groups, GP's and Physiotherapists. This allows for the continuation of care for patients moving through the health care system.

The working day begins at 8am for most of the staff and almost immediately they are inundated with people making enquires about how they can get their relative/friend/self onto the long list of patients cared for by the hospice. On my first morning I travelled, along with three other staff, to the Inanda Club, Johannesburg to attend a conference being held by "Metropolitan" and the "South African Business Coalition for HIV/AIDS" (SABCOHA). The event's aim was to inform local organisations

of the outcomes of a recent conference held to discuss plans for limiting the spread of HIV/AIDS throughout South Africa. The site states "the only true weapon in the fight against AIDS is information".

I spoke to a number of people about their views and beliefs of the subject and what I was told surprised me. Due to the different cultural backgrounds in South Africa, many belief systems exist, making the role of informing the general population of the risks of AIDS an extremely difficult task. One example recently documented in the media has been the belief that having sexual intercourse with a child will rid a person of the HIV virus. This shocking belief may unfortunately be leading to the further spread of the disease. Therefore, it is necessary to inform people of the true causes and of the best ways to avoid contracting HIV.

There is a well recognized problem with HIV/AIDS in sub-Saharan Africa. During my stay I met so many people with the condition that it is easy to believe whatever action is being taken is failing. In the Mamelodi satellite hospice the patients are composed of 60 HIV/AIDS and 30 Cancer sufferers.

For the vast majority of my stay, I worked with the Nurses that visit patients in their homes. These visits allowed for wound care, personal hygiene and medication administered to be carried out. However, for a large proportion of the time the visits centred on care, support and bereavement counselling. Witnessing death, dying, severely infected wounds and legal conflicts were other aspects that I encountered. It was a fantastic learning experience and although I felt physically and emotionally drained on a number of occasions, wherever possible I offered my assistance to anyone who needed it.

I was keen to do some work in the Townships and the hospice was only too happy to accommodate this. I worked with Ethel, a nurse of Nkosa origin, in the Mandela village, an informal squatter camp in Far East Mamelodi. The houses here are built from corrugated iron or thin brick walls extended with Zozos, small shed-like constructions. The buildings are small, dark, damp and freezing in the winter. People staying there have the bare minimum to survive on and many have large families living in one tiny room with basic sanitary facilities. Once again the care involved a great deal of bereavement counselling and advice giving.

On one visit I met four generations of women living together having lost all the males in their family with the most recent death due to AIDS. I came across a 27 year old male AIDS sufferer as he was warming himself over a tiny paraffin camping stove. His mother was having problems caring for him due to financial difficulties and although the Hospice had tried to arrange support for them nothing had yet arrived. They were living on next to nothing and it was amazing how helpless it is possible to feel when presented with a situation that you can do nothing to rectify.

There were however some other encouraging stories such as that of a mother whose unborn baby had been at risk of contracting the HIV infection from her at birth. The use of an anti-retroviral injection at birth had so far protected the baby from the virus and he was as yet showing no signs of disease.

Some other children had not been so fortunate and in the Mamelodi hospice I was working with two young boys: one of 2, the other 3 years old. Both had contracted HIV at birth from their mother who had since died as a result of this disease. The Grandmother was now caring for the

two boys. A strange phenomenon is taking place in South Africa. The older population, instead of becoming the ones that are cared for, are once again becoming the carers as a whole generation is dying and leaving young children without parents. The Sungardens Hospice allocated a day out every week for the children labelled "AIDS Orphans".

On one occasion I travelled with Dr Cameron to one of his clinics. We drove for two hours through the Moretele District to the rural village of Mathibestad. I was surprised to find a female Doctor from Aberdeen working in the clinic and it was strange to hear a Scottish accent. While in Mathibestad I took part in a training course being run for nurses in rural districts which I found extremely informative. I then worked with 5th year medical students on "Rural placement" from the University of Pretoria taking histories and examining new patients.

One patient I am sure never to forget was a young woman who had been having a long run of medical problems. After working through all her symptoms and then negotiating with her Bossiedokter it was decided that she should continue with both forms of treatment, traditional and modern. As she was getting up to leave she mentioned a slight pain in her ear which had been present on and off for around two years. The Doctors felt this was due to wax build up and decided to syringe it. I observed the process and everyone assumed this would have a typical outcome until, as the procedure went on, the student I had been working with noticed an insect antenna protruding from the woman's ear! Additional doctors were called in for assistance and eventually a dead Cockroach was removed – I was later informed that you can expect to see cases like that a lot in Africa!

Over the course of my stay I was given many opportunities to further my learning. Dr Cameron invited me to The University of Pretoria Satellite campus to attend a lecture he was giving to 4th year medical students. He also took me on ward rounds in the IPU allowing me to practice some practical skills and while also teaching me signs and symptoms to watch

out for. After each patient the doctor gave me an overview of the condition and an explanation for the observations we were making.

On a few occasions what I saw and heard shocked me. For example the Cheyne-Skokes breathing pattern, also known as the "death rattle", a sign of the last stages before death is a sound I had previously never heard. By the end of my visit however this had become a sound I recognised. On one occasion Dr Cameron and myself were some of the last people to see a female patient before she died. I then accompanied a Nurse to the woman's family to carry out the initial bereavement visit.

Seeing the pain and grief of patients before death and that of their families after death, was always a sad event. It demonstrated how important it is to remember that behind every illness there is a person, a family and a whole number of issues that may not be immediately obvious.

My stay in Pretoria was one of the most rewarding and valuable learning experiences I could have hoped for. This trip will influence my studies and also my future career path as I have now acquired skills and seen situations that simply would not have been possible otherwise.

In the hospice ethos they state that "coming to terms with death is as important as coming to terms with life and may provide profound insights into the purpose of living". I could not agree more.

My sincere thanks go out to the staff and patients at the Sungardens Hospice, Pretoria, South Africa.

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See www.royalmedical.co.uk for application forms.
