

Palliative Care in Malawi

*Adding life to days, when days
cannot be added to life*

Report of elective placement at Ndi Moyo Palliative Care Centre, Salima
February – April 2014
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MALAWI IN NUMBERS

Population 15,906,000 (WHO, 2012)

Life expectancy at birth 54.8 years
(UNICEF, 2012)

HIV prevalence 10.8% (UNICEF, 2012)

25% deaths caused by HIV/AIDS
(Bowie, University of Malawi, 2011)

9th highest prevalence of HIV
globally (CIA World Fact Book, 2012)

\$77 spent per capita on government
healthcare (WHO, 2012)

46% of patients live within 5km of
a health facility (Malawian Ministry of Health, 2004)

3.4 nurses and midwives per 10,000
population (WHO, 2013)

Estimated number of doctors 265
(UK Department for International Development, 2012)

90.4% of the population live on less
than \$2 per day (FINCA, 2014)

One of my key mentors throughout my path to and through medical school has always been a key of a 'place giving life' in Malawi – a palliative care centre.

Inspired by this countryside GP from Gloucestershire, I felt that perhaps this could be the place for me to spend my elective. I got in touch with one of the two founders, Tony Finch about the possibility of spending my whole elective period at the centre. I was keen to undertake just the one placement in the period, to allow myself the opportunity to settle in, adjust, and then really get involved.

I'd never really been taken by palliative care itself as a specialty in the UK, but it seemed like it was an entirely different beast in Africa: a dangerous combination of severe resource limitation, poverty, and the HIV/AIDS epidemic. It seemed to present a true opportunity to put my recently tested knowledge to use, hopefully pass on some skills, and develop myself as a clinician and individual.

I left a flooded Oxford in February 2014, nervous and excited. I arrived in Malawi halfway through its rainy season, just weeks after a corruption scandal was unveiled in which the state has been defrauded of almost 1% of Malawi's annual GDP in just 6 months, in a systematic looting of public money by senior political figures.

Ndi Moyo was founded in 2006 by Lucy and Tony Finch

Ndi Moyo (Chichewan for 'with life') is a hospice providing outpatient palliative care in Salima and the surrounding area, near Lake Malawi.

Lucy Finch was born and raised in Malawi, and left for the UK to train as a nurse. Here she met her husband, Tony and they had their children. In March 1997, Lucy met Dr Anne Merriman, the founder of Hospice Africa Uganda. She invited Lucy to become a volunteer nurse at the Hospice in Kampala. This was Lucy's first introduction to palliative care, and highlighted to her how it was the essence and ethos of good nursing care.

In 1998 Lucy was called home to Malawi to nurse her sister in the last weeks of her life. Whilst at the Armed Forces Hospital that her sister was a patient in, she met a young soldier dying in pain. He screamed in pain for three days, and the only analgesic that the hospital had was paracetamol. Lucy promised herself that she would never again place herself in the difficult position of having the knowledge but not the means to help a fellow human being who was suffering so much. She felt that she had to somehow start palliative care in Malawi.

Lucy and Tony left Uganda for Malawi in 2002, but it took until 2006 to find the financial backing for the centre, and the building to host it in. Ndi Moyo opened

its doors to patients 1st August 2006, and was officially opened in June 2007 by the then Minister of Health, the late Mrs Marjorie Ngaunje.

Ndi Moyo is a small oasis in Salima, a busy town of 40,000 people which is situated at the junction between two main roads, one north-to-south, and one from the capital city, Lilongwe, to the lake. On its small site, there is the main clinic building (formerly a bank), an administration building, and a beautiful garden.

As well as being decorative, the gardens are used to grow plants used in natural remedies, from moringa to make a tea used in anaemia, to artemesia which is made into an ointment which seems to cure most skin problems (including the itch of my own insect bites!).

The clinic building houses a small pharmacy, two private rooms for consultations, and other spaces that have been adapted as best they can for seeing patients. Unfortunately, Ndi Moyo has largely outgrown this building now, and it is not really suitable for the size of the clinic it now hosts.

Later this year, a large project to build a new, purpose-built clinic building will start, on a site just at the back of the Ndi Moyo gardens. Having larger, well designed clinic facilities will be a huge boost for the centre.



Above: Lucy and Tony Finch

On its clinical team, the centre employs one clinical officer and four nurses. The clinic is currently overseen by Kathryn Hamling, the Clinical Director who is over from Fort William, Scotland volunteering, and works as a palliative care nurse in the UK. Kathryn also oversees the day-to-day running of the pharmacy and clinical administration.

The clinical staff have access to basic examination equipment; thermometers, a blood pressure machine, and stethoscopes. The single diagnostic test available at the clinic was a rapid test for malaria.

Patients that require inpatient treatment or therapies that cannot be provided by Ndi Moyo, e.g. IV antibiotics, are referred to Salima District Hospital.



Working at Ndi Moyo

Left: The morning prayers and meeting of patients and staff

Whilst I had been briefed by one of the UK trustees of Ndi Moyo, a medical doctor, before leaving for my elective, the reality of working in a resource poor country truly hit home in my first few weeks in Salima. Most weeks followed a similar timetable, with daily outpatient clinics, twice-weekly hospital rounds, weekly outreach clinics, and frequent home visits.

Starting the day

Each day at Ndi Moyo starts with a meeting of patients and staff, with prayers and singing (usually in Chichewa). Then the patients leave the circle to form a queue outside the clinic building, sitting on green, plastic patio-furniture chairs, whilst a staff meeting, and then a subsequent clinical meeting takes place.

The clinical meeting serves as a time for discussion of notable patients and issues from the previous day, and any problems that are anticipated to arise during the day ahead. Any new admissions are also discussed as part of the meeting as case presentations, with the team talking about key learning points arising from the patient and their management.

Patient education

After the clinical meeting, the patients waiting for the outpatient clinic are given a brief talk by one of the nurses. The topics of these talks vary from contraception and the prevention of sexually transmitted diseases, to the basics of writing a will. Such education is hugely valuable to the patients, who have little opportunity of obtaining such information elsewhere.

Outpatient clinics

The main work of Ndi Moyo lies within its onsite outpatient clinic. Many of the consultations between patients and clinical staff here were straightforward, consisting of a discussion about symptom control, any new problems, and a renewal of prescriptions. I mainly saw patients in conjunction with one of the nursing staff, or the clinical officer. Very few patients spoke more than a few words of English, and with my level of Chichewan normally similar (or worse!), translation was normally required.

The most common conditions affecting patients enrolled on the Ndi Moyo programme are Kaposi's sarcoma, cervical cancer, and oesophageal cancer. Both Kaposi's sarcoma and cervical cancer are HIV and AIDS related cancers, whilst it's likely that the high incidence of oesophageal cancer is linked to nitrate fertilizer contamination of drinking water. Nitrate fertilisers are heavily relied upon by

'The reality of working in a resource poor country truly hit home'

much of the Malawian population in order to grow adequate amounts of subsistence crops, primarily maize.

Patients with these cancers often need similar problems managing: nociceptive pain, neuropathic pain, bleeding, anaemia, and minor infections. Pain management was a particularly challenging issue, with only a limited selection of drugs available: paracetamol, ibuprofen, diclofenac, amitriptyline, and liquid morphine.

Most of the drugs are dispensed from large 1000 tablet containers into pill bags that are then given to the patients – it's far more cost effective than blister packets. Liquid morphine is measured out in the pharmacy, and then dispensed to patients in recycled plastic water bottles – Malawian resourcefulness in action.

Although many of the patients at Ndi Moyo present with similar problems, the clinic is occasionally thrown the occasional curveball. One afternoon of a busy clinic day, I was asked to come and help the clinical officer assess a patient who had just been discharged from the TB ward at the district

Below: Dispensing tablets and liquid morphine in the pharmacy



hospital, having completed her mandatory two weeks of treatment in isolation. This young woman in her thirties was clearly very sick, and had a recent diagnosis of HIV, not yet on ARVs, and a probable diagnosis of Kaposi's sarcoma. On further assessment I found her to be in shock (T 40.3°C, P146, BP 87/34, R36) with no clear focus of infection. With no further diagnostic tests available, we agreed to send her straight back to the female ward of the hospital for IV fluids and antibiotics. She survived that hospital admission, and was discharged home. As my time at Ndi Moyo ended, she had been admitted once again, with severe shortness of breath of unknown cause.

Salima District Hospital

Clinical staff from the centre visit Salima District Hospital (SDH) twice a week, and combine the visits with taking Kaposi's sarcoma patients there for their chemotherapy.

SDH is a second-tier health care facility, with only one doctor (who now is working as the in the administrative role of District Health Officer), and the rest of the clinical staff either being clinical officers or nurses. It has male, female, paediatric, obstetric, and isolation wards. The Malawian government aims to offer a free healthcare system for its citizens, which results in some differences in the care a mazungu (Westerner). There are invariably always more patients than beds, leaving some patients sleeping on woven mats on the floor. Furthermore they are principally cared for by family members ("guardians"), who stay on the hospital

site. Drugs are also provided for free, providing that they have supplies available in the hospital pharmacy; if they're not, sometimes patients can purchase their prescription from a nearby private pharmacy.

Kaposi's sarcoma patients receive either single agent chemotherapy, of vincristine alone, or dual agent chemotherapy, adding in bleomycin. The vincristine is given with an intravenous injection, and painful extravasations are upsettingly common. Bleomycin is given intramuscularly. It is difficult to ensure that the hospital maintains adequate stocks of bleomycin – and in fact it ran out during my placement – to allow the 24 patients we had on dual chemotherapy to continue their courses. During my time there, Ndi Moyo staff were talking to the hospital pharmacy, warning them well in advance that their stocks were about to run low, and even offering to collect the drug from the capital city and take it to the hospital under cold chain conditions. Fortunately, the centre had a "plan B" in place, and had acquired some bleomycin for their stocks from a charitable HIV/AIDS centre, so patients could continue with their treatment.

Whilst at the hospital we also aimed to see any inpatients that were enrolled on the program, and any referred to us by the hospital staff. Common reasons for our patients to be admitted include infections and severe anaemia.

Getting a blood transfusion for an anaemic patient always managed to prove difficult, for one reason or another. Firstly, there is no formal, large-scale blood donation service in

Malawi, so patients must rely on a donor match amongst their relatives willing to donate for them. Secondly, the hospital had to have adequate stocks of the reagents to test the donor and patient blood; including blood group, haemoglobin level, and Hepatitis B and HIV status. The third hurdle whilst I was at Ndi Moyo was the availability of blood donation bags; no longer available at the hospital, but could be purchased for K4000 (around £6) at a nearby pharmacy. Haemoglobin levels of less than 6.0 g/dL were not uncommon.

There are seldom patients on the Ndi Moyo program in SDH, but the staff still make regular visits to the children's ward, to check if they need liquid morphine (it is not uncommon for morphine in any form to be unavailable in the hospital). This morphine is then used for children with burns, a sadly common occurrence as Malawians cook on open fires, and toddlers often pull down pots of boiling water onto themselves. I came across two children with burns on my hospital visits: one a boy with 25% body surface area partial thickness burns, which included his genitalia; the other a girl with 15% body surface area partial thickness burns, which spared her left eye by just millimetres. I learnt that such cases are even more common during the winter months of June and July.

Outreach clinics

As Ndi Moyo aims to serve patients in the whole of Salima District, it has three different monthly outreach clinics at government health centres, aiming to bring its services closer to those patients living furthest away. This made sense

from both the patients' point of view, and from that of the centre: aiming to maximise patient attendance whilst minimising the centre's costs for providing transport support.

These clinics also offered a good opportunity to meet other health care professionals at the health centres that we visited. With rows and rows of benches filled with patients, including children and breastfeeding mothers, it was plain to see just how overstretched such facilities are. Patients only get a few minutes with a clinical officer, scarcely any privacy, and a quick scribble in their health passbook.

Home visits

Ndi Moyo provides a home-based care service to its patients who have limited mobility, or are nearing the end of their lives.

I felt hugely privileged to be able to visit such patients at home; I got to visit remote villages in the bush that I would never have otherwise had access to.

Visiting patients in their homes offered a real insight into their day to day lives, the strength and courage that they show, and the love and support that their families give to them. Much of this reminded me of patients I've met back in the UK, and shows me how universal some traits can be.

I met with patients in a variety of different accommodation set-ups. Whilst some had brick walls, plaster, electricity, and tin roofs, others had only a leaking shelter of a thatch roof and plastic sheeting. I will forever remember a gentleman who lived in the latter accommodation. Despite his physical condition being such that he was completely immobile, and entirely dependent on others for even the most basic of his needs, he was chatty, engaging, and a real delight to spend time with.



Above: A patient receiving intravenous vincristine chemotherapy



Kaposi's sarcoma behind the ear causing facial oedema

Making the most of limited resources

The Malawian government spends \$77 per capita on healthcare, a miniscule amount compared to the \$2820 spent by the UK government, or \$4000 spent by the US government. Consequently, its healthcare resources are hugely limited, and it seems all the more important to try and maximise their value.

Chemotherapy records

During my placement at Ndi Moyo, it became apparent that it wasn't always easy to keep track of which Kaposi's sarcoma patients were regularly attending for their chemotherapy. As a result, it was common for patients to default on their treatment; a potential problem both for the patient receiving an incomplete therapy, and the hospital who have then incurred the cost of giving the patient this therapy.

This problem seemed to partly arise due to patients no longer attending for therapy once they felt better, an issue that had been discussed by the clinical team on multiple occasions previously. We discussed how best to structure the conversation that is had with patients prior to starting them on chemotherapy, to try and ensure that they understand the commitment that it entails.

Further to this, I then started to look at how best to keep simple, up to date records of the chemotherapy received by patients. One of the nurses at the centre had a spreadsheet that he had started using to keep records. I used this as a starting point to then create a spreadsheet that allowed easy inputting of chemotherapy attendances, which clearly showed when a patient had defaulted.

Patients at Ndi Moyo receive either single or dual agent chemotherapy. Single agent therapy with vincristine starts with six weekly doses, followed by six fortnightly doses, and then six monthly doses. Patients on dual agent therapy receive twenty fortnightly doses of vincristine and bleomycin. The spreadsheet thus had to highlight if a patient had not attended within their currently chemotherapy interval, comparing the last date they attended to today's date.

I trained the nurse who had generated the original spreadsheet to use the new one whilst I was at Ndi Moyo, and he ran it as a trial for one full week of chemotherapy patients before I left the centre. I hope that my work will allow the team to identify defaulting patients earlier, and get them restarted on their treatment sooner.

Antibiotic prescribing

Another area I noticed where resources could be better allocated was with antibiotic prescribing. With no diagnostic tests available, the clinical staff more often than not erred on the side of caution when it came to antibiotic prescribing; it was common to find amoxicillin prescribed for a simple cough.

I created guidelines to help the clinical staff to diagnose infections, and ways of treating them (aside from prescriptions), along with a standardised prescription, using a drug from the Ndi Moyo formulary. We had a group discussion session once these had been created, and talked about cases we had come across where each guideline may have been applicable.

I handed over the guidelines to Kathryn, the clinical director, and hope that the guidelines and standardised prescriptions will now be used. Before I left Ndi Moyo, we also discussed the potential of using these guidelines as the basis for an audit by a future medical student placement; to see if their creation had been implemented, and if it had changed antibiotic prescribing practices and created an awareness of antibiotic stewardship.

A particularly shocking case of Kaposi's

One case that I found particularly shocking was that of a man in his 40s who I first met in Salima District Hospital. He was known to Ndi Moyo, and was HIV positive with disseminated Kaposi's sarcoma. He had developed cellulitis in his Kaposi's lesions, and underwent significant debridement performed by the clinical officers at the hospital. He was left with the tendon sheaths on the dorsum of his foot exposed, and several deep sinuses in his calf. I was particularly worried about him as I felt that it was unlikely that these wounds would ever heal: he had Stage IV HIV and woody oedema in the affected leg up to the hip. He spent most of the duration of my elective in hospital on IV antibiotics, but was discharged not long before I left the centre. His wounds remained very extensive, and I still question the decision to debride him so extensively, when there was no clear evidence of necrotising fasciitis, and important further management resources, such as skin grafting, are not available in Malawi.

An extremely heart-breaking paediatrics case

Another case that especially difficult to deal with emotionally was that of a 16 year old boy with Hodgkin's Lymphoma. He presented at the clinic

very unwell, and clinically very anaemic. His Hb measured 1.3 at the hospital, and it came to our attention at he had not seen a health care professional about his cancer for two years. According to his health pass book, he had been diagnosed with his disease at a stage at which it has a 90% cure rate with appropriate therapy. He had received two cycles of chemotherapy down at the large government hospital in Blantyre, but his family had not been able to afford the transport costs to take him back for the further necessary cycles. Consequently his disease had progressed, and he now had massive hepatosplenomegaly, severe anaemia, and was experiencing high fevers with no obvious focus of infection. We provided this boy and his father with antibiotic cover and comfort fund money (approximately £20) to return to Blantyre for further assessment and possible treatment. We sadly heard that he passed away 2 weeks later.

Travelling in Malawi

I was lucky enough whilst on elective to be able to visit numerous places in Malawi, often meeting up with other Oxford elective students along the way. My travels have provided me with some truly memorable experiences, including travelling on the back of a pick-up with scores of other Malawians, cardboard boxes, and a goat; and being charged by a temperamental teenage bull elephant whilst on safari.

The value of the experience

My elective has been an experience that I feel has really allowed me to develop as a clinician. I am now far more aware of the importance of treating the symptoms that a patient is experiencing, without getting completely side-tracked about getting a diagnosis 'label'. I am much more confident whilst working, and am realising just how much I have learnt and developed over the past three years of medical school.

I would like to thank Green Templeton College, The Beit Trust, The Feoffees of Tetbury, and The Association of Physicians, as without their kind support this trip would not have been possible.

Below: A baby elephant in Majete National Park

