THE

APLI News

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Palliative care in Cambodia

'education in any form...would improve their knowledge base, skills and confidence enormously'

Dr Michael Barbato; July 2002

I have recently returned from 2 weeks in Cambodia. The visit was prompted by a series of e-mails from friends currently doing volunteer work within one of the two hospices in Phnom Penh. What they described was heart wrenching and I decided to see first hand what was happening in palliative care and whether opportunities exist to help at an individual or organisational level (APLI).

Given the brief nature of my visit I decided to spend most of the time at the hospices, one a 60 bed unit run by the Missionaries of Charity and the other a small 12 bed facility run by MaryKnoll, an American based Catholic Order. There may have been other hospices in Phnom Penh but as with most things in Cambodia it was hard to track down factual information. There are certainly numerous non-government and charitable organisations doing many good things but I came away with the impression that little is coordinated. MSF is certainly active throughout Cambodia and their doctors are responsible for the care of AIDS patients in a large Phnom Penh hospital.

I met many fine individuals doing wonderful humanitarian work including one NZ doctor who had been there for 3 years and a retired US banker who gives much of his time and money to assist with the care and education of Cambodia's homeless, of which there are many. Both hospices had many expatriate volunteers including some who were also working for NGOs in Cambodia. I had the privilege of meeting an elderly Cambodian man, who after 40 years of living abroad had decided to return 'home' to do volunteer work in one of the hospices. His day started at 7am and finished at 5pm and he did this 6 days/week. I too did some volunteer work and despite my relative youth I was exhausted after a mere 6 hours.

Talking about age, it is worth noting there are not many people my age in Cambodia. The reason for this lies partly with their tumultuous past but equally with the poor standards of living and health care. When asked how old I was (a commonly asked question) most responded to my answer of 60 years with the comment "Oh so old" and from thence on insisted on calling me 'papa'. That was a nice show of respect but I hardly felt I deserved it and what's more it did little for my self-esteem.

I did not see one case of cancer during my time in Cambodia. AIDS is the overwhelming health

Editor's note

In this edition, we have an article from Dr Michael Barbato describing his recent visit to Cambodia. He reports "AIDS is the overwhelming health problem and the commonest cause of death." Dr Barbato hopes to maintain the links he made while there and to undertake further visits. We wish him well in his efforts. We also reproduce, with permission, items from the African Hospice Foundation e-news. The sheer enormity of the HIV/AIDS tragedy is apparent in these newsletters. It is heartening to read of the American assistance through Hospice linkages. If anyone wishes to be included in the email-outs of this group, contact Peter Sarver on PSarver@hospicecny.org. I wonder how APLI could promote this model in the Asia-Pacific area? We have heard from two hospice directors in Africa, interested in forming links with palliative care people here in Australia, perhaps you might like to make contact and see what develops?

2002 was a quiet year for APLI (but not so quiet for Odette Spruyt and Liz Bearzatto (publisher), both of whom were off on maternity leave. 2003 looks to be a more active and challenging year for APLI with plans to produce quarterly newsletters and update our website.
In particular, we will be working to establish APLI as an incorporated association.

We are grateful to all our regular contributors and hope to see more articles from our friends in the Palliative Care community throughout the world.

Best wishes, Carol Douglas (email: drcarol@bigpond.com)
The Editor

From the editor's desk...

Palliative care in Cambodia *continued...*

problem and commonest cause of death. The incidence of AIDS is thought to be much higher in Cambodia than in any of the neighbouring countries. Numbers are hard to come by but one reliable source told me there are 200,000 known and countless unknown HIV positive people in a population of 11 million. The main avenue of transmission is heterosexual sex but concerted efforts to educate the masses about condoms has to date had a poor result. Comparisons were made with Thailand where condom usage is nearing 100%. It may be fact or fiction but the reason for this high compliance was said to be because a Thai Government minister owns the condom factory.

The two Khmer doctors who worked with MaryKnoll had a smattering of English and were able to communicate reasonably well. Both were relatively new graduates and admitted to struggling with the volume of work and the challenges associated with AIDS. They had very little knowledge of palliative care principles and the virtual absence of analgesics other than paracetamol and codeine made its practice somewhat theoretical. Most of the myths surrounding morphine are very much alive and when morphine becomes more available, much education will be required to ensure its appropriate use. Most of the patients we saw were end stage and while little symptomatic treatment was available to ease their distress most continued to receive large numbers of pills for cryptococcus, tuberculosis, toxoplasmosis etc until the time of death. I had until then thought this was only a western phenomenon.

Abdominal tuberculosis was a very common diagnosis, often made on ultrasound and confirmed by a clinical trial of anti-tuberculous medication. Lymphoma was an unheard of complication of AIDS and I wondered how many of those that failed to respond to medication did in fact have lymphoma. Naturally this was purely academic, as treatment for this complication was non-existent.

The hospices themselves were somewhat dark and depressing by western standards but offered much more in the way of comfort than did the average Khmer home. The MaryKnoll hospice located in Phnom Penh had 12 beds and accommodated adult patients only. There were 2 beds to a room but little space for anything else. Day to day care was provided by locally trained Khmer women, a health worker administered medications and a doctor visited each day. The hospice was always full with an inevitable overflow of 1 or 2 patients accommodated on a small verandah. The Missionaries of Charity hospice was much larger with beds for 20 infants and children and a further 40 beds for adults, all in dormitory style wards. This hospice was 20km outside of Phnom Penh and was run by the nuns with considerable help from health workers and volunteers. Most patients had end stage AIDS but a few of the children had cerebral palsy. There was a separate ward for tuberculous patients who, for a variety of reasons could not be cared for at home or indeed had no home. A doctor visited this hospice on a weekly basis.

The MaryKnoll Hospital, Phnom Penh

Apart from the regular hospice round, I also sat through outpatient clinics, which started at 7.30 am and finished when the patients stopped coming, usually well into the afternoon. I also accompanied doctors on their home visits, which often took them 30km out of town to resettlement camps where living conditions were as poor as you are likely to find anywhere in the world. As many of these people are squatters they have no legal rights to basic sanitation and water, and live under appalling conditions. Sadly discrimination is a big problem and those with AIDS are often afraid to identify themselves for fear they will be forced to leave their home, camp or village. Such discrimination is not confined to the poor and uneducated. Anything other than life-saving surgery is not permitted within 'public' hospitals on those who are known HIV positive.

Health problems are exacerbated by poor hygiene and housing. Malnutrition was common and dental caries widespread. Many of the houses I visited could only be entered after wading through ankle deep mud. Most were 'constructed' of canvas that was neither water nor wind proof. Belongings were almost non-existent and food sparse. Skeletal dogs were testimony to the absence of any food scraps.

Health facilities were primitive and poor treatment exacerbated by a shortage of doctors and nurses as well as unregulated dispensing of drugs. One of the hospital wards I visited had no windows or doors, no nurses, cleaners and no food services. The only doctors that visited were from MaryKnoll and this they did voluntarily. They not only supplied their skills but also offered medication when they could. MaryKnoll also paid for 2 of their staff to attend to the patients and supply food if relatives were unable to provide this.

Many of the sick are turned away from hospitals because they are unable to pay for the legal or illegal costs up front. Wages are so low that most of the employed resort to any means to supplement their income. 'Tips' almost guarantee treatment within a hospital but those that could not pay were either turned away or given emergency treatment and then sent home. It was not uncommon therefore to see mothers riding as a pillion passenger on the back of a 'moto' (small motorcycle) carrying a sick child in one arm while holding an IV in the other. A recent Urban Health report estimated that those in the poorest areas could only afford a few dollars for health care so it is not surprising to see these people resort to traditional healers or seek medication from drug stores as an alternative to hospital. One of my neighbours in Choum Chow (a small village outside of Phnom Penh) went to the hospital because of a possible foreign body in the eye. A five-minute consultation in a 'public' hospital set him back $20 US whereas the chloromycetin eye drops I purchased from the drug store cost $1. His monthly income was a mere $15.

Palliative care in Cambodia *continued...*

You can buy almost any drug from drug stores providing you have the money. Simple medications are cheap but life saving or life prolonging drugs are costly. For example generic anti-retroviral drugs that cost $27/month (US) in Thailand costs as much as $200 in Phnom Penh. On my one and only visit to a drug store I was surprised to find many of the antibiotics and anti-malarials that would normally grace an Australian hospital dispensary. The resident 'chemist' has no training but learns most of his/her lessons from the greatest and most universal of all teachers, trial and error.

Phnom Penh is a remarkably flat city of one million people. It bustles with motos that weave through streets overflowing with people and traffic. Walking is a dangerous past-time and footpaths if present, are fully occupied by parked motos, makeshift homes and curbside businesses. I often took to the streets on foot but was constantly harassed by moto drivers who clearly felt that walking was for the insane and that a ride on their machine was the next best thing to luxury. If one was unlucky enough to be caught in a tropical downpour, ankle deep water ran like rivers, dirt turned into mud and water accumulated in potholes that could swallow a careless moto driver as well as a pedestrian. Traffic rules appeared to be non-existent and the only thing that challenged the noise of constant horn blowing were demonstrations outside garment factories or music announcing a wedding or a funeral.

The people themselves were friendly and always eager to communicate as best they could about their life or mine. One of the highlights of my trip was when my moto driver for the day stopped outside of a small home on the outskirts of Phnom Penh. Despite the language barrier it was clear this was his home and that he was eager for me to meet his family. I spent a wonderful 30 minutes there and left feeling privileged to have shared such a spontaneous and generous gesture.

A typical street in Phnom Penh

Before I left Cambodia I asked the doctors what they needed to make their work easier. The list was long and included more doctors, nurses, better facilities, and access to all forms of medication both symptomatic and curative as well as books and journals. While most of these were long-term goals they agreed education in any form was the easiest of all to achieve and would improve their knowledge base, skills and confidence enormously. I am currently looking into ways to make this happen and already have been encouraged by generous donations from Mims and information and resources offered by ASHM.

It is hard to ignore the problems of Cambodia and the discrepancy that exists between life there and that of the western world. Solutions will always be temporary while this state of affairs continues. Sadly this may be harder to solve than any of the problems I have alluded to in this report.

I plan to return to Cambodia early next year and do more voluntary work but in the interim I will look to improve my Khmer and become more familiar with tropical medicine and the latest trends in HIV/AIDS.

News from Africa dominated by AIDS epidemic

These items are taken from the African Hospice Foundation e-news and reproduced with permission from Dr Peter Sarver.

First Phase in Malawi Hospice Development Funded Foundation for Hospices in Sub-Saharan Africa (FHSSA) has received word from an anonymous US Foundation that it will fund African based hospice experts to provide consultation in Malawi, a country with a population of more than 10 million. The initial aim of assessment will be followed by program development making hospice care widely available. The $5,000+ grant will enable FHSSA to facilitate a review of hospice needs and responses through the Malawi HIV/AIDS Partnership, an NGO coalition established in 2001. The project goal is directed toward helping 75% of Malawi's villages be provided with community based hospice services by 2005. With a HIV seroprevalence rate of 20% Malawi faces enormous care giving challenges.

Message from Tanzania

Dr. Mark Jacobson with Selian Lutheran Hospice writes that the Arusha based home hospice care program has received a grant from FHSSA to extend hospice training to other hospitals in Tanzania. "We are just bursting with joy and want to share with you. Today we finished the first week of training for other hospitals in Tanzania. We had four other hospitals attending – Wasso in the Serengeti, Nganga to the west, St. Stephens from the very south, and Machame near Kilimanjaro. It was a wonderful seminar and all four hospitals are committed now to hospice. Wasso has already begun its hospice program

but now we see Tanzania going from one to five hospice programs! All a result of Selian and the SubSaharan Africa Hospice Foundation support. I am near tears with the blessing that this is to our people."

Zimbabwe Initiative

INTERCHURCH Medical Assistance (IMA) is developing a project which will provide "infectious disease"' health care kits for the use of family members who are caring for their loved ones with HIV/Aids and other health problems. Zimbabwe has been identified as a potential site for implementation as many of IMA's member agencies have church related connections in the country. Unfortunately this project is emerging at a time when Zimbabwe is faced with intense political and economic turmoil.

A widow's story from Zimbabwe

Gaundencia Musekiwa writes in the latest issue of Island Hospice News that "since the death of my husband, his relatives never came back to look after their relative's children. So it is just a matter of fact that I am on my own throughout the rest of my life. It is now four years since the departure of my husband, and they never bothered to share the burden. However, last December, I phone Jenny Hunt. We discussed the loss of my husband and she comforted me. She gave me Island Hospice notes to read which provided me with actions to do if I lost someone I loved. Every night I would read the notes and visit Jenny once a month. One day I jumped with joy when I was donated a sewing machine by Island Hospice. I used to repair damaged clothes. Later I started to sew boys' Shorts and started selling them. Having noticed I was gaining a profit, I started sewing peg hanger bags and dishtowel bags. Walking from township to township I saw life was improving. I can now manage to pay school fees for my children. I can also buy material and sew good outfits for my kids. From deep down the bottom of my heart, I really feel I was saved by Island Hospice."

Personal Experience in Namibia

Among the persons we hear from regularly in Africa is the National Coordinator for the Catholic AIDS Action Lucy Steintiz. She offers this latest reflection – "Last night we visited friends and then attended a fund-raiser concert that was put on by the American Cultural Center on behalf of Catholic AIDS Action and another organization. But this morning, we learned that the brother of this same friend whom we visited had died overnight of AIDS. And so we've already been back to her home three times – once with soft drinks to share with the other mourners, and twice just to pay our respects. The funeral will probably take place next Saturday or even the week-end afterwards, just as soon as all the relatives can gather around, and everyone is sure that enough money has been raised from family and friends to pay for the coffin an funeral expenses. We offered one of the paper-mache coffins we're making, but I think the family wants something fancier. Tragically, there is also a wife involved (who is probably also infected) and a one-year-old daughter (whose HIV status cannot yet be determined), so the future still holds a lot of uncertainty and loss. This is the second HIV-death in as many weeks among people we know in Namibia. As the pandemic ages, more and more people pass the symptom-less stages of HIV-infection to full blown AIDS and death. Yesterday I visited a new Municipal cemetery that had just opened in November, and noticed that over 150 graves had already been filled, including at least 20 small plots for infants. Not all these deaths were from AIDS of course, but when you walk past them and see that so many of the burials were for young people in their twenties and thirties, the cumulative impact of this disease begins to hit you.

African American Hospice partnerships

(part of the FHSSA program to match African and American hospice programs)

The Helderberg Hospice, Somerset West, Western Cape Province with Hospice of Western Reserve, Cleveland, Ohio.

Helderberg Hospice has 23 nurses, 11 community health workers, 288 volunteers and 3 physicians serving 288 patients in Y2000. Home based care program backed up by small inpatient unit. HIV/AIDS: 79% target population.

St. Bernards Hospice, east London, SA and Broward-VITAS in Florida.

St Bernards has 3 nurses, 4 volunteers, 3 community health workers, 1 physician and 1 social worker, serving 878 persons in Y2000. 70% patients were HIV+ve.

Naledi Hospice, Free State, SA with VITAS Healthcare corporate office, Miami.

Staff of 6 nurses, 23 community health workers, 45 volunteers, serving 1620 patients, 580 of whom were children in Y2000. 75% patients were HIV+ve.

Interested in linking up?

Call to members of APLI interested in forming links with:

Dr Carla Lamadora,
Island Hospice Service, Harare, Zimbabwe
island@mango.zw

"interested in expanding our international links. If anyone is ever headed to Zimbabwe, we would be delighted to hook them up with us."

Dr Peter Kraus, St Luke's Hospice, SA
tracey@stlukes.co.za

"very keen to develop links with other individuals with respect to palliative care services."

Links with Nepal Daya Vaidya, nurse educator, B.P. Koirala Memorial Cancer Hospital, Chitwan:

"BPKMCH is opening a 10 bed hospice care centre, but due to lack of manpower, cannot open yet. Need help with education of doctors and nurses, perhaps spending two weeks to one month there.

Hospital will provide accommodation and local transportation from Kathmandu to Chitwan, (150 miles).

80% patients in hospital are in terminal stages. (APLI note: ideal arrangement for a doctor and nurse to travel together and spend extended period assisting in establishment of services.

Contact Marie Coughlan, nurse educator, email: mcoughlan99@hotmail.com Sydney, NSW, who assisted in this way in Bangalore, India).

IAHPC Award

The Medical Director of Hospice Uganda, Dr. Anne Merriman has been chosen as the person to receive the 2001 Annual Individual Award by the International Association of Hospice & Palliative Care. Dr. Merriman was cited as having "worked very hard in Uganda and many African nations in promoting the development of palliative care." Her role as "an advocate for policy changes" and her help "in the development of new programs and initiatives" were mentioned among the reasons for the honor.

OPAL

Overseas Pharmaceutical Aid for Life collects unwanted pharmaceuticals for distribution overseas to countries in need. Contact Geoff Lockyer at OPAL, 500 Churchill Road, Kilburn, South Australia. 5084. Phone 08 8359 6055

Conference News

- see APLI website for contact details

EAPC 8th Congress
The Hague
April 2-5, 2003
eapc@kenes.com

Hospice and Palliative Care Nationals Association Seminar
The Hague
30 March – 1 April, 2003

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If you are interested in giving ongoing support and in assisting in the work of APLI, please ensure that your membership is up to date by the end of 2002 so that you will be eligible to vote on the important issue of incorporation of APLI.
Note : once we have been incorporated, we will send out our ABN with receipts.

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