



THE APLI News

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Asia Pacific Hospice Conference May 2001 –Taiwan; feedback

Dr Molly Mathew

Kota Kinabalu, Sabah, East Malaysia

There were about 800 participants with of course 80% from Taiwan itself but it was amazing how such a small country could have such a large number of Palliative Care enthusiasts.

The speakers were great. I think all of us benefited tremendously from their knowledge and experience in palliative care and most of all the camaraderie between people doing the same work. The key to how they made Hospice a household name in Taiwan lies in "Team Work". They pulled together, each one with various strengths and talents and that is the magic of their success.

Prof. Maddocks (Australia) emphasized that the "practice of palliative care calls for a way of doctoring which is unhurried while being busy, attentive rather than prescriptive, patient in listening rather than active in advising. It sits by the bedside and does not edge quickly towards the door, it takes advice from the family and nurses. It deals calmly with uncertainty, it tries something different, evidence or not". Prof. Kashiwagi (Japan) feels that "to care for another person is in the most significant sense, to help that person both to grow and to be able to actualize his or her true self"

Maybe, cancer is the best way to die. That is what Dame Cicely felt. It gives us time to be – a second look at life maybe.

Many speakers gave us an insight to spiritual pain and the psychosocial needs of patients and family. Patients often tell their needs differently to different people. Our own beliefs influence the way we behave with others.

"Spiritual Care for the non religious patient" by Dr Suresh Kumar was another well attended session. We must remember that we are responsible to our patients and not responsible for them. There is spirituality in relationships. We must maintain and reestablish old ones, and however much we try we can never extinguish the pain of parting. Communication between our patients, between colleagues and especially in the home is important. Complementary therapy could help in spirituality, continually creating a trustful safe environment.

All the talks and discussions gave us a deeper and wider understanding of Palliative Care medicine but most of all the meeting enhanced fellowship between counties and of course most reassuring to know that herein Kota Kinabalu we have an excellent unit and also a good home care program supported by all the volunteers (Palliative Care Association)

In Enoch Lai's (Taiwan) words "all of us have a dream and if everybody works towards the same end, dreams do come true." ☺

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Editor's note

Welcome to another Occasional Newsletter of APLI. We are delighted to have a further letter from Dr Sailaja in Trichur, India and to be able to continue the "Regular Letter" feature of this newsletter. We hope such correspondence might expand and would encourage others (thank you, Daya) to write to us with their experiences. It is a wonderful way of giving insights into the day-to-day challenges and successes and to share these with each other.

We are planning to distribute the newsletter more widely through the networks now well established in the Asia Pacific region and elsewhere. In this way, we hope to foster links with our colleagues in Asia in particular. The newsletter is also sent to the IAHPIC (website address www.hospicecare.com <<http://www.hospicecare.com/>>) and the Hospice Information Service, at St Christopher's, London and through them, to many colleagues throughout the world.

Hello from the editor...

So please send articles on any aspects of your work, future meetings, new developments in your region. Let us know if you wish to be linked to a service or tell us about links you have established. Are you planning to visit another palliative care service either to teach or to learn? Let us know of your experiences.

We hope to have another newsletter out before Christmas this year, an opportunity for you to let others know your news.

With very best wishes, Carol Douglas.

The Editor

Note from Nepal

Namastay and warm regards.

I am sorry for my delay in writing. I was so busy because my cousin had breast cancer and my mother was sick for few days. In caring for them I could not make time to write you soon after I came here.

B.P. Koirala Memorial Cancer has started a 25 bed hospice center but I wonder when it will be completed. From last few months our hospital became so much politicised that is very difficult to work.

Also, makes it difficult to write detailed information about palliative care in Nepal. There is no doubt that at our hospital about 85-90% patients are terminally ill and most of them can not be offered cancer treatment nor can they be offered pain- killer medication. There is no choice for the poor with cancer.

Patients accept 'wait and see' or die with pain. I am very frustrated when I see them but I am helpless as I have no authority and no power.

In this situation I asked myself why I studied cancer nursing. If I know nothing I will not feel it is so unfair being poor. Though, those who can offer some treatment also have limited access to palliative care as there are limited health professionals who have knowledge of palliative care.

There is belief that cancer has no cure so not worth to treat so majority of patients and their family cease the treatment and go home and wait for death.

This does not mean that Nepali cancer patients' families have no love, they are so poor that they could not afford for the treatment. One of the patients who came to hospital said that "if I am not going to be cured, I prefer to save my money for my children" so he refused to treat himself.

My working environment is also not good. There is many things behind it.

Bye love from Daya

Letters from India -

'Family is, and should be, the pillar of strength for the patient'

Dear brothers and sisters,

Hello once again, it is Sailaja from India.

I thought that this time, I will tell you something about how it functions on a typical day here, in my clinic.

The OPD starts functioning at 8.30am. I go to see the in-patients first, before starting at the OPD.

The patients are referred to me from oncology as well as other departments; and I prefer to see them in my OPD room rather than in the wards, so that I could give them enough time, space and privacy.

The patient is definitely addressed.

Equal importance is for the family too. As you know, here in India, and I believe anywhere in the world, family is and should be the pillar of strength for the patient. But it is not the fact every time.

There sitting in front of me is a family of four-the parents and two children. The father has been diagnosed as having lung cancer and he is the sole breadwinner of the family. His wife is asking me "we will sell our house and treat him but could you ensure us that he will be cured and will take care of us again so later we could buy a new house?"

The very next day, there sits a father with stomach cancer and his son. Both are surgeons. The father tells me to counsel his son so he could accept his father's diagnosis and treatment choices.

Here the state does not pay for the health care of its citizens. So a course of treatment for malignancy could 'shatter' most of them financially and emotionally.

Yes, of course, being a charitable institution, our hospital management is doing their 'bit' Approximately crore rupees is given as charity every year. Still there are people who just abscond from treatment for financial reasons. You may think this is to be an exaggeration, but poverty here is to that extent that it may be unimaginable for you.

Still, we are not desperate. I try to be pleasant and sincere to the last patient of my OPD list. In return they take me as their daughter or sister and discuss their personal and family matters with me.

Recently, a tough situation had to be handled. A 50 year old farmer was diagnosed as having advanced lung cancer. His family was informed about it and the futility of any treatments at this advanced stage. After entrusting the patient to his brothers, the wife and only son went home and committed suicide by consuming an insecticide. The brothers wanted to collude the

information from the patient; as they thought that he might not survive the news.

He was getting palliative treatments. At the time of admission he was dyspnoeic and psychologically dependent on oxygen. He even asked for euthanasia. But after giving him time and symptom relief, he was told about the family tragedy. He took it boldly and gave instructions to his brothers about how to handle his property, and even about organ donation!!!

In the fourth week of his admission he was relaxed physically and mentally; and passed away peacefully while he was asleep. The remaining members of his family including

the two brothers who took care of him in the hospital were so surprised and thankful that somebody with cancer can remain without pain and distress, like this, even at the time of death!

I think it was the most rewarding moment for us when the younger brother came tearful to the OPD after arranging the transportation of the body for the last rites and thanking us saying that this is the best way his brother could pass away from this world.

The time, energy and emotions spent on him were really worth it. Don't you agree? I am sure you do, because human suffering, emotions, frailty and feelings of helplessness are the same everywhere.

**Your loving sister,
Sailaja ☺**

Palliative care in Papua New Guinea



I recently spent 8 weeks from 3rd June 2001 in Papua New Guinea (PNG) sponsored by the International Association for Hospice and Palliative Care (IAHPC) to promote Palliative Care. My family and I had lived and worked in PNG for 15 years in the 60s and 70s, and with only two brief visits in 1989 and 1999 I was pleased to return and renew old friendships and make some new ones.

The main diseases where palliative care is required are cancer and AIDS. It is believed that there are about 15,000 new cases of cancer per year of which 10,000 die, and many of them in pain. Probably most cancers are never diagnosed. The commonest types (cervix, mouth and liver) are increasing in incidence, although they are largely preventable. Mouth cancers have been shown to be related to chewing betel nut with lime, both of which are carcinogenic, cigarette smoking being an additional risk factor. However betel nut is a source of cash for many city dwellers, who sit along the footpaths selling the nuts and cigarettes as single items. As in other countries, cervical cancer is associated with promiscuity and poor genital hygiene. Hepatitis B virus (HBV) is the most important aetiological factor in hepatoma, although about a quarter are associated with cirrhosis. HBV vaccines should help prevent this disease.

Unfortunately most malignancies present at a late stage. In many patients it is inappropriate to attempt radical surgery in patients with advanced disease, when chances of cure are slight and the patient risks dying in a hospital a long way from his village.

A radiotherapy service with a Cobalt unit was opened in Lae in 1972, but the (second hand) machine broke down 2 years ago and is not repairable. There is no medical oncologist either, although chemotherapy is given based on protocols left by a visiting oncologist.

AIDS has recently become a significant problem. To 30th June 2001, 3901 cases of HIV infection had been reported with 1366 cases of AIDS and 249 deaths. Here again, the majority are probably not reported. The peak age incidence in those diagnosed is 19-24 in females (many through antenatal clinics) and 25-29 years in males. Most AIDS is transmitted through heterosexual sex.

The country is unable to afford anti-retroviral drugs, so the need for palliative care is paramount. AIDS is now the commonest cause of death among patients of the medical units at the Port Moresby General Hospital (PMGH)

I spent the first 3 weeks at Port Moresby. I attended meetings and ward rounds and had discussions with doctors, nurses and pharmacists at PMGH, PNG's major hospital with over 700 beds. I also suggested treatment for cancer patients in pain and gave lectures and conducted seminars for doctors, nurses and medical students.

Visits were made to the Department of Health and the Medical School from which 20-30 doctors graduate each year.



CONTINUED: Palliative care in Papua New Guinea

During the next 3 weeks in Lae I also attended ward rounds and spoke at meetings with staff of the ANGAU (Australian New Guinea Administrative Unit) Memorial Hospital, and the adjacent School of Nursing. About 10 years ago the Japanese government donated a large new wing to both the PMGH and ANGAU hospitals.

Finally I spent another 2 weeks in Port Moresby during which time I:

- Conducted an in service study day for nurses.
- Arranged a meeting of senior clinicians to recommend a list of drugs for palliative care, based on a discussion paper I circulated.
- Attended the first day of a National AIDS Council workshop in Goroka to give a lecture/presentation on palliative care for patients with AIDS.

Problems in Relation to Palliative Care in PNG.

Pain

Frequently not recognised or addressed. PNG people are said to be "stoical", probably not realising that pain relief is possible. Busy medical and nursing staff may not recognise that the patient is in pain. The nurses at Lae translated a verbal descriptor pain scale into Pidgin English and it was combined with a "faces scale" to measure pain intensity.

AIDS

Families are frightened of AIDS so that some patients are abandoned. Education is needed about transmission and how to nurse patients, so that families understand that there is very little danger of infection of carers.

Access to Analgesia

The most effective medications for pain and symptom control are often not available, particularly opioid analgesics. Buprenorphine, papaveratum (both rarely used) codeine and pethidine (both used frequently) are available from the catalogue. Morphine was available only as a 10mg SR tablet (therefore rarely used) and 10 mg/ml injections. Morphine powder, used to make morphine mixture,

had been out of stock for 7 months in Port Moresby, but was available in Lae, although out of date.

At the meeting mentioned above, a range of doses of SR morphine and 30mg/ml injection was added and buprenorphine and papaveratum omitted. The list was approved by the Pharmaceutical Advisory Committee.

Maintenance of Supplies

There are problems maintaining supplies of essential items. As well as morphine powder, X-ray films, oral contraceptives (combined pill), 4% dextrose saline solution and intravenous cannulae were out of stock during my visit. Regular supplies of analgesics in particular need to be available, both for hospital patients and also in rural areas for those who go home to their village to die. This is a long-standing problem.

Education

Education in pain management and palliative care is necessary for all levels of health worker. During my visit I gave 16 lectures, tutorials etc to groups and had discussions and promoted palliative care to 53 individuals. I am returning in September to give a paper at the Medical Society Symposium and hope to be further involved in educational activities in 2002.

Conclusion

Funding is not available for existing health programmes. I believe that these problems need to be addressed on a countrywide basis involving as many health workers as possible, rather than setting up small groups to give high quality care in a few locations.

I have the highest regard for the PNG doctors who continue to faithfully practice medicine under very difficult circumstances. I am very grateful for their assistance and friendship during my visit.

Dr Nell Muirden

Palliative Care Specialist, Centre for Palliative Care, Melbourne, Australia 

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

9th National and International Conference of the IAPC

Varanasi, INDIA
February, 2002

IASP 10th World Congress on Pain

San Diego, California
17th-22nd August, 2002

Australian Bioethics Association 'Global Bioethics Exploring Alternative Approaches'

Adelaide, AUSTRALIA
14th-16th February 2002

Editor's News

Dr David Brumley has taken up the role of Treasurer for APLI as of June 2001, following the retirement of Dr Mick Barbato. Once again, many thanks to Mick for his dedicated support and a warm welcome to David. Those of you who are members of ANZSPM will already have enjoyed David's calm efficiency and competence and no doubt APLI will benefit also greatly from his experience.

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