APLI News
Volume 18
Issue 1 February 2014

Editor's Note

"Without purpose in travel, it would probably be better to suffer the ennui at home. I want to offer you a way to immunise yourself against meaningless travel."

So wrote Dr David Brumley in our APLI newsletter last Dec 2012. As I read this again, in Trivandrum, Kerala, India, where we (Alan, the boys and I) spent the month of December, these words resonate strongly with us. To be offered the chance to connect with and contribute to the work of colleagues across India whose dedication, intelligence, and kind welcome is always humbling, is a great gift and one for which we are very grateful.

This newsletter brings you news of developments in India, Sri Lanka, Myanmar and the region. Project Hamrahi continues to grow, thanks to the generous contribution of doctors and nurses in Australia and the openness and desire to improve of our Indian colleagues. The new Lakshadweep link is showcased in this edition. It was a first on many fronts. The first time an NGO visited these islands. The first time an advance trainee provided the mentoring through Hamrahi. The first time APLI and Pallium combined staff in the one visit, with Dr Abu Laize, Pallium India, travelling with the Australian team (despite his first child's birth almost coinciding with the visit). Abu had previously visited and worked with the Lakshadweep team and also provided essential knowledge and assistance with cultural and language translation .The first time the team had to travel off the mainland of India on a Hamrahi visit. The first link established with a service which was commenced by a non-medical citizen who recognised and responded to the unrelieved suffering of people with advanced illness. This visit meant a great deal to the Lakshadweep people and we aim to provide additional support to their efforts in 2014.

In addition to the Hamrahi project, APLI has been active in teaching, collaborating in the inaugural 6 week intensive palliative care course of Pallium India, in Jaipur. This was the first time this course was held in northern India, beginning on 24th November and our congratulations go to Dr Anjum Joad, a palliative care leader in India, who established the course at the Bhagwan Mahaveer Cancer Hospital and Research Centre, Jaipur.

The tragedy of unavailability of opioids for pain management in India continues largely unabated, with only few places successful in bringing about meaningful change. Once again, at the time of writing this note, the bill was before the Indian parliament, in their December sitting. Once again, the parliament failed to discuss and pass the Bill. We understand that the current parliament will have one more sitting, in February, and our Indian colleagues will be pulling out all stops in their efforts to have this Bill passed, before the current government disbands and critical relationships lost!

With best wishes to all for 2014

Odette Spruyt

Inside this issue

APLI News acknowledges the support of MUNDIPHARMA

Project Hamrahi feature

A meeting of minds and hearts: Lakshadweep Hamrahi 2013

Dr Lam and Ms Sarah Rose with Thanal organisation members and Dr Abu Laize Salins

As the Air India flight landed on a turquoise water-surrounded runway on Agatti Island, this months-in-the-planning adventure finally felt like a solid reality.

Stepping onto the tarmac where the humidity enveloped us, we pulled out our cameras to record this first landing on Lakshadweep whilst excitedly anticipating the upcoming helicopter journey to the capital Kavaratti Island. This flight was the final step to bring us to our hosts and Project Hamrahi colleagues. Twenty minutes later, via our first helicopter ride ever, the three of us alighted at Kavaratti Helibase to be greeted by a delegation of staff from the Lakshadweep Institute of Palliative Medicine. The warm, earnest and enthusiastic hospitality which welcomed us from this moment would be present in all the rich experiences we would have over the next 5 days.

Dr Abu Laize Nd Jumaila, Assistant Project Manager with Pallium India in Trivandrum, Clinical Nurse Specialist Sarah Rose and I were visiting a fledgling palliative care service in Lakshadweep as part of Project Hamrahi.

Arial View of Lakshadweep.

It had taken many months of administrative navigation to allow this historic first visit by a foreign NGO to the island of Kavaratti. The Lakshadweep Institute of Palliative Medicine had inaugurated only 8 months previously and was driven by the vision and passion of a local teacher and unofficial community leader, Moulana.

The service was community-based palliative care and at the time of our visit actively seeing over 50 patients either as regular visits or via a 24 hour on-call service. The service was tirelessly staffed entirely by unpaid volunteers and led by Moulana acting in a social worker capacity. His dedicated team included one 'fulltime' doctor and nurse (Dr Ali and Brother Khafee) who had both undergone a 6 week training course at the Trivandrum-based Pallium India Institute in February 2013, 6 other nurses and 13 'volunteers' who had the rather nebulous role of identifying suitable patients and supporting families.

Ms Sarah Rose and Dr Lam with community patient in her home.

Project Hamrahi feature (*cont. from pg2*)

A meeting of minds and hearts: Lakshadweep Hamrahi 2013

Inauguration of Hamrahi project, Lakshadweep

The service had good initial support from Pallium India and was a registered morphine prescribing service. Medications, equipment and staff time were all provided free of charge to patients and referrals were taken from all sources with quite varied needs across the physical, social, psychological and spiritual spectrum. Operating in an isolated area that had no home-based medical or nursing services at all, the complexity of patient needs was also quite varied. Sarah and I saw patients with very basic wound care needs to others with more complex psycho-social issues.

Over 5 intense days, Abu, Sarah and I were immersed in the culture, sights and community of Kavaratti island. Zooming around the islands roads, beneath the swaying coconut trees, we visited around 30 patients in their homes as well as a handful of consult patients in the Indira Gandhi Hospital. In addition, a grand round presentation on palliative care was delivered at the hospital, an inauguration ceremony attended as honoured guests on the dais, and formal teaching sessions with the palliative care staff prepared. To assist in raising the profile of a palliative care service in need of financial support, we also presented ourselves before numerous officials and administrators.

Mr Moulana, with Ms Sarah Rose and patient, on a home visit

Amidst this activity, innumerable cups of sweet tea with snacks were consumed in offices, patient homes and the homes of our hosts and their friends. It was immensely rewarding to see patients and their families in their homes and to appreciate the real difference the presence of palliative care services made. A key challenge for this service is the lack of consistent funding. It was established with the help of a 1 year medication supply grant from Pallium India and otherwise relies on donations mostly from staff. In addition, only two staff have received limited formal palliative care training. However while the service was quite resource limited, it was remarkably well resourced in spirit and enthusiasm. They need a political and administrative will to fund an ongoing service and we hope that the Hamrahi collaboration can help not only with knowledge and experience sharing but also with awareness and perhaps fund raising. Already planning our return visits, Abu, Sarah and I left deeply moved by our experience and quite motivated to try and help this community and service sustain a long term presence.

Dr Lam with young patient at home, Lakshadweep

Sophia Lam, Sarah Rose.

Brief reflections on visit to Jaipur:

I was given the opportunity to visit India by my colleague Assoc Prof Odette Spruyt. Odette had asked me to consider volunteering as a clinical nurse for the APLI Hamrahi projects she had founded in India. I had never been to India and never done any formal volunteer work overseas in the developing world. After much deliberation and joining APLI, I plucked up the courage to say I would be available to volunteer in 2013.

Having made that decision I was still questioning if I had what it takes to make a significant contribution to the sick of India. I am an experienced clinical lung cancer nurse and very committed to the philosophies of palliative care for both the living and the dying. Dr Anjum Joad invited us to participate in the first 6 week training course to be held in Jaipur, Rajasthan, in the north of India. A reassuring timetable of lectures for the first week was drafted by distance between India and Australia, lists were drawn up and plans were made. But could I teach? Would I be more of a burden to my fellow traveller than a help? I was extraordinary nervous and excited though about the trip.

My passage to India was extremely easy, thanks to Odette. We met in Delhi and travelled together on a flight to Jaipur. We were met by a colleague of Dr Anjum Joad (Maam) and taken to the Bhagwan Mahaveer Cancer Hospital & Research Centre (BMCHRC) where we would stay for the week. Entering BMCHRC for the first time I was initially struck by the similarities and at the same time the differences with my own place of work. I felt a connection with the centre from the beginning. Everyone was friendly, hospitable and quietly curious. Hospital employees were easily identified by the uniforms of varying colours they wore. Large smiles and colour were themes for the week as we made our way daily to the palliative care hub of the hospital which was Maam's office. All corridors led there. Anjum's office had this amazing 'open door' policy at all times. Staff, visitors, patients and families all knew where to find Maam. Anjum's passion, commitment and dedication to palliative care in the centre was apparent in everything she did all day, everyday.

Anjum's office doubled as a place of refuge for us for the week as we regrouped there, made changes to the timetable and lectures and adjusted to the uncertainty of the day in a flexible way. Our motto was expect the unexpected and deal with it, and we were never let down. Students turned up daily which was reassuring. A total of sixteen students enrolled in the course, many of them nurses. Despite IT challenges and changing venues, we did five full days of teaching. Topics I covered were breathlessness, supportive care and symptom control, qualitative research using my Master's as an example and subcutaneous infusions(S/C).

Brief reflections on visit to Jaipur *(cont from pg3)*

I quickly realised that lectures prepared in Australia needed a new approach. We determined Case Studies from daily clinical practice would complement our classroom learning well. So each day the students presented a case study on a patient they had assessed with a member of the team. Emphasis was on keeping the patient, their symptoms and management at the centre of what we were teaching for the week. Odette was known as Maam for the week. I was 'Miss Mary'.

Students were eager to learn how to communicate with patients, how to talk with them, provide information and reassurance. Case study's enabled us to share how to conduct a physical assessment on a patient. They requested hands on demonstrations on how to provide physical care for the patient confined to bed. We demonstrated how to change the position of patients in bed, change bed linen at the same time as maintaining patient dignity and privacy and communication, including the importance of touch and nonverbal means.

Odette and I had some Graseby pumps to donate to the centre. We provided a demonstration on how to set it up, care for the patient, and discussion around why they are used.

Our week was busy, fun and hopefully useful to the students that attended. I also hope we kindled an interest in palliative care that will be useful to patients in the future. I learnt a lot from being there and from Odette. Not just on palliative care, but on life in India and life in general.

I felt really alive in Jaipur, every sense on high alert all the time. Fantastic colour everywhere. Beautiful people. We had great food, didn't get sick or have problems with mosquitos thanks to Bushman's and long sleeves. At times I feel a fraud as I did have an easy introduction to India. I am still asking the question, can I teach?

Mary Duffy

A return to Cachar Cancer Centre

Having visited last year under the auspices of Pallium India and APLI, Sarah Corfe and I decided to return to Cachar Cancer Centre, in the rural town of Silchar in Assam. We had enjoyed ourselves so much there last year, and were, we thought, quite close as we were both attending the APHC meeting in Bangkok. Sadly Oliver Haisken couldn't be with us this time, but gladly Ofra Fried, a palliative care physician from Townsville, agreed to join us. On the way to Suvarnabhumi airport in Bangkok for our flight to Calcutta and Silchar, we were a little anxious as we listened to reports of Cyclone Phailin thrashing the East coast of India. We needn't have worried: the worst we experienced was a windy night in Calcutta.

But there is always anxiety when returning to a place where you've previously enjoyed yourself. Will it be the same this time? Am I remembering correctly? We need not have worried about that! We were once again met at the airport in the hospital ambulance, but this time we had arrived at the time of Durga Puja, which is possibly the most significant social and cultural festival in the Hindu Calendar. Since the festivity includes huge numbers of processions, bound for every bridge in a place of rivers, it was a long, happy, noisy and exciting drive to the hospital!

We met up once again with the Director Dr Ravi Kannan and his wife Seetha, and with Dr Iqbal Bahar, the palliative care physician at the hospital. They were as welcoming as ever, and we were cared for very well once again, with superb meals cooked by Seetha.

The hospital itself has grown. Last year the top of the hospital was sprouting steel rods, but this year they had been converted into more levels of hospital and will soon be occupied as new wards, operating theatres and accommodation. Cachar Hospital is becoming a model for rural cancer care. It is run with great energy, enthusiasm and dedication, and it attracts resources from elsewhere including professional staff volunteering there in order to learn from the hospital's exemplary practice. As an example, we met two volunteer gynaecological oncology surgeons during this visit.

The Palliative Care Service had developed significantly since our previous visit. Last year, Project Hamrahi funded two of the nurses to attend palliative care training in Trivandrum. Sarita, the ward manager and Achun, a senior nurse returned with new skills and ideas, and have been educating other staff since then. The atmosphere in the ward is very positive, and the nurses raised many concerns which, interestingly, were not so different from those we face in our Western palliative care practices! Seetha had already met with the palliative care staff, canvassed ideas, and prepared an extensive teaching program for the three of us to cover during this second visit. She said the nurses were "like sponges" in their keenness to learn, and we certainly found them so. Their level of formal nursing training was very variable, and we taught across several language barriers, with the participants, who were themselves from a variety of ethnic and language backgrounds, translating amongst themselves.

The biggest new initiative in palliative care at Cachar is the development of the home care service, largely staffed by senior nurses with the support of Dr Iqbal This is no mean feat in an area of deep cut rivers and floodplain, where roads are difficult and flooding frequent in the wet season. The service faces the same problem we face here: the costs in time and transport are very high. But in other ways the situation is radically different. In this river valley live 3.5 million people, and the town of Silchar itself is more than half a million. All three of us enjoyed a day out on house calls with nursing staff. We enjoyed discussing ideas about teleconferencing and perhaps video conferencing to reduce travel costs, and look forward to sharing more ideas about that.

We enjoyed a great farewell (actually two, since I (DB) left earlier) including a very funny parade of local costumes and displays of dancing and singing. Sadly, all I could manage was a feeble and croaky rendition of Kookaburra sits in the old Gumtree! Sarah and Ofra danced the night away to Bollywood themes, to the great amusement of the locals.

As I've said before, we always learn more that we teach in these visits, and my learning this year included some tutorials in abdominal ultrasound from Dr Iqbal. This is one of his many talents.

Farewell again, Cachar, but we may be drawn back yet again by your enthusiasm, your skill, and your wonderful hospitality. Thank you again.

David Brumley
Sarah Corfe
Ofra Fried

APLI Sites Throughout India

Updates from the region

India

Integration of palliative care into oncology practice in India - "the need of the hour"

Indian Cancer Congress, New Delhi, 21 – 24th November, 2013

Participating in the first Indian Cancer Congress in New Delhi provided opportunity for another encounter with India. She opened her arms as always and shared her wonders and woes, with this enamoured guest.

The conference was an ambitious and pivotal event, the first interdisciplinary national oncology meeting to be held in India, with all cancer subspecialties represented, from pathology screening, diagnostic imaging, psycho-oncology, palliative care and oncology clinicians from radiotherapy, surgical and medical disciplines present. In India, many oncologists practice both radiotherapy and medical oncology, with the distinction between these apparent only in the major, better resourced, academic or regional cancer centres only. There was prominent drug and device company sponsorship, displaying products in a

ICC, New Delhi, November 2013

"the need of the hour" *(cont.)*

Communication plenary, ICC, Delhi, 2013.

(cont from page 5)

large tented area a short walk from the conference hotel. It was wedding season in India and a large temporary pavilion decorated in the style of a palace, abutted the industry tent, making the space festive and joyful.

Palliative care featured throughout day 1, beginning with an overview of the progress of the development of palliative care in India presented by Prof. Rajagopal of Pallium India, and followed by plenary sessions on communication, presented as a panel discussion led by Dr Chaturevedi, Bangalore, pain management and its impact on quality of life, presented by Dr Suresh Reddy, from the MD Anderson, post operative pain in the cancer patient and finishing with a discussion about opioid availability in India.

The sessions were attended by the palliative care registrants, with few practitioners from other disciplines. Still, the inclusion of palliative care in this first conference was a welcome sign, and the program organised by Dr Sushma Bhatnagar, from AIIMS, New Delhi, was excellent.

Palliative care in India is now 25 years of age and has made many notable advances. However, until the Narcotic Drugs and Psychotropic Substances Act is replaced, the realisation of effective pain management for all patients across India with cancer and other disabling, painful conditions will not be realised. In discussions at the conference, an oncologist voiced his strongly held beliefs that opioids should not be used for painful cancer-related conditions such as post-mastectomy neuropathic pain, while still demanding effective pain management from the palliative care forum members. His strident views exemplified the ongoing need for education and attitude change. The onis is on us in palliative care to grow the research and clinical practice literature to challenge and change such opinion-based medicine.

The presence of the pharmaceutical and manufacturing industry at this conference was felt strongly. Many attendees were there thanks to sponsorship from this industry. The recent publication in the JCO (1) discussing the dangers of pharmaceutical company-determined drug costs is a pertinent reminder of the risks of the unsupervised relationship between clinicians and pharmaceutical industry. Unethical practice is a cause of intense suffering for patients and families who bear the cost of drugs and must be strongly regulated.

Pain management and palliative care needs to be more accepted and integrated into cancer care in India, in recognition of the advanced stage of disease on presentation of the majority of patients in this subcontinent. Enhancing the knowledge and skills and changing the attitude of oncologists in this aspect of cancer care is critical for the achievement of best practice cancer care in India. In addition, a primary care workforce with similar skills, working with trained health care workers, would reach the most remote locations, as is evidenced in the state of Kerala. The need for many more courses offering basic training in palliative care practice, and ongoing opportunities for refresher courses and clinician exchange of expertise and experience is very clear.

The MD 3 year program in palliative care established in Maharastra 2 years ago, offers the only 2 places for advanced training in palliative care in the whole of India. Meanwhile, many practitioners are either from the vanguard of palliative care development in the country, most of whom are experienced practitioners of specialities such as radiotherapy or anaesthesiology, or from non specialist practice, early career doctors who chose to work in palliative care from the outset. Most of these have received a diploma from Cardiff, UK or Flinders, Australia, some in collaboration with the APHN. This group are in need of concerted assistance from their colleagues in IAPC to advocate to secure their place as specialist practitioners within palliative care. The grand-fathering arrangement which achieved this in Australia has no precedent in India and the political will of the medical establishment beyond palliative care appears to be lacking or indeed resistant to such a practice. This does not augur well for the growth of the speciality. Palliative care needs to be recognised as an equal amongst other disciplines if it is to attract young doctors into this field.

I look forward to visiting India again soon.

Odette Spruyt

Reference 1. Kantarjian H.M. et al. Cancer drugs in the United States:Justum Pretium - the just price. JCO 2013:31(28);3600-3604

Jaipur Intensive Palliative Care course

As Anjum answered yet another call on a day of 94 mobile phone calls, countless queries in person in her hub office, & phone calls on landline on this fourth day of the first north Indian 6 week intensive palliative care Pallium India Jaipur course, I could only marvel at her equanimity, good nature, humour and kindness to all comers.

Previously head of the anesthetic department at BMCHRC, Jaipur, for 13 years, palliative care pioneer here, Flinders/APHN graduate and chosen for the IPM leadership course in the USA, Anjum is a leader in the true sense of the word. She is willing to take and shoulder risks, to teach by example, and to lead by dedicated and generous service. She is tender with the uncertainties and frailties of junior staff, not expecting more than they are capable of delivering, yet encouraging them to stretch their capacity and to take responsibility where possible. The young women residents respond with grace and respect. Her office is a haven and a hub of activity. She is variously seen in her anesthetic greens, white coat for ward or OPD consults or day dress to perform a more official function. The PC services began when the cancer centre opened, one of five subspecialties at the inception and her standing in the organization is clear to see. Everyone knows and respects Dr Anjum.

In keeping with her leadership capacity, Anjum has started the first intensive palliative care course in northern India. The course began on 24th November with nursing students, resident doctor, community volunteer of nursing background, dental researcher, and palliative care nurse as the first course participants. The M.Sc nursing students lapped up the information, and especially valued the practical sessions on nursing care, patient assessment and communication. These students had little patient contact so far in their course which is the trend in nursing training in India, it seems. Language proved more of a barrier for the nurses than for the students.

Mary Duffy, lung nurse coordinator at Peter MacCallum Cancer Centre in Melbourne, was a huge hit with the students. Her blend of academic knowledge, passion for and love of nursing, and years of cancer and palliative care nursing experience gave these students new insights into nursing practice and what caring for patients means. From lessons in positioning patients with respiratory distress, to how to introduce yourself to a patient, to how to present a patient's assessment concisely, the students and Mary overcame cultural and language barriers with humour and the desire to learn. The sharing amongst the group grew as the week progressed.

Mary Duffy teaching positioning of the patient (Dr Anjum Joad) at the inaugural Pallium India Jaipur intensive palliative care course.

(cont from page 7)

The course aims to cover the management all the common symptoms in cancer and other illnesses, psychosocial care and communications skills training and to expose the participants to palliative care practice in consult, community and inpatient settings. It needs to be responsive to the differing levels of expertise and experience of diverse participants. It encourages interaction between students and teachers to make learning less threatening and more enjoyable. Specialists from areas such as rehabilitation medicine, psychiatry, & cancer medicine are invited speakers according to availability.

The week in Jaipur included an interview with the Hindu Times reporter to speak about the urgent need for reform of the NDPS act of India and raise awareness of palliative care.

We all enjoyed an outing to the beautiful Jal Mahal, on the lake in Jaipur, in the middle of the week. The students were naturals in front of the camera!

Odette Spruyt

The nursing students with Dr Anjum Joad and Odette Spruyt at Jal Mahal, Jaipur

Refresher course, Pallium India

7-8 December, 2013

This opportunity to regroup and share experiences in palliative care practice is one of the many courses provided by Pallium India to grow the level of palliative care practice in India.

The course was attended by diverse practitioners in terms of age, specialty, familiarity with palliative care and outlook. The latter was apparent in discussions about relaying prognosis and attitudes to the patient with uncontrolled pain. The respect for seniors within the learning group was apparent and the care with which younger participants expressed contrary views (or did not speak up at all) was noteworthy to one used to the more outspoken style of Australians.

The two days were spent discussing difficult pain management, other symptoms, management of urinary incontinence, prognostication, & leadership, with day two dedicated to communication skills training. Most participants were from Kerala and some were currently undertaking the six week intensive palliative care course.

It is always a learning experience to be asked to assist with teaching in India. Practitioners here are very experienced doctors who come to palliative care with many different motivations and backgrounds. Some have attitudes which are hard to appreciate. Being a foreigner limits the efficacy of challenging truth telling, as the East -West difference is held up as a reason to discount what might be challenging to individuals practice. However, when Prof Rajagopal encourages more respectful open communication, such excuses are no longer tenable. An interesting discussion took place about the word "by-stander" to refer to family members caring for patients in hospital. Some felt this was understood and acceptable to Indian patients and family, others told stories of distress at being addressed or spoken of using this word and finding it distancing, diminishing of the relationship which they felt they had had with the physician.

Hopefully, there will be further opportunities to participate in these courses in future.

Odette Spruyt

Group work, refresher course, Pallium India

Pallium India celebrates 10 years

On 13th December, Odette, myself and our two boys were privileged to be present at the 10th anniversary celebrations for Pallium India. It was an all day celebration of games, speeches, food, music and dancing. We presented Pallium with a birthday card on behalf of APLI, congratulated them on their work and thanked them for the opportunity to partner them in Project Hamrahi. Hamrahi is proving to be of benefit to all involved and we look forward to this fruitful collaboration continuing.

Alan Hebb

At U Hla Tun Hospice Mandaly

Grace Buchanan, Palliative and Supportive Care Education Team Manager, Cancer Council Western Australia at the Training Centre.

Myanmar Visit in November 2013

The opportunity to visit U Hla Tun hospice Yangoon and Mandalay was realised for Dr Meg Sands and Grace Buchanan this November for one week. The invitation from Mr David O.Abel, Brigadier General hospice Chairman was extended after his and his delegations visit to Australia in May 2013. This visit was made possible by Mr Abel, the generosity of Mr. Clive Triplett and the support of APLI.

The aim of the visit was to continue the dialogue following on from the delegation's visit to Australia earlier in 2013, in order to exchange views and ideas on various issues in palliative care treatment and training. The visit echoed the sentiments of the November APLI Forum "Sharing knowledge, establishing relationship". Education, training, and mentoring opportunities in the Myanmar hospices with emphasis on symptom management at the end of life were identified as a focus for present and future collaboration.

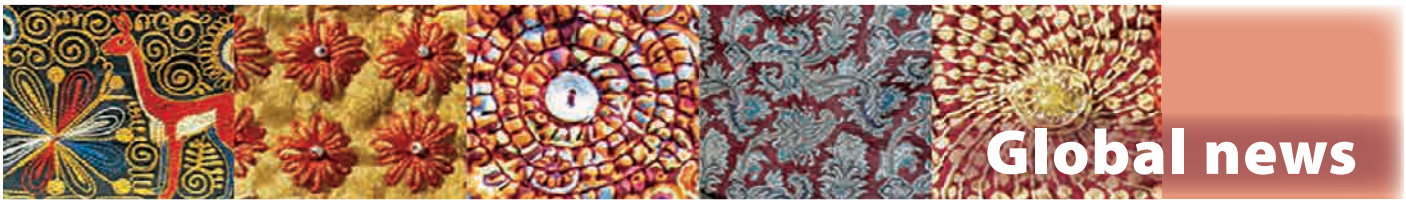
Within Yangoon, palliative care education courses have commenced which are being delivered by APHN over a series of modules. Two of the cancer hospice staff are attending. We are looking at ways to ensure that any ongoing support and education enhances and reinforces these modules.

The philosophy of the cancer hopices in Myanmar is to care for the poorest of the poor in the community in an inpatient setting. We were privileged to be invited to meet the staff in both sites and have the opportunity to meet some of the patients and their families. The kindness and generosity of everyone that we met was humbling. The hospices Motto "Our Duty is to care, care is to Share" is a lived experience for all staff within the multidisciplinary team that delivers care at both sites. The hospices are non-government run companies funded by the initial donation of the founder and are administered by the 2 boards and the executive staff.

From this visit the team members of the hospice have outlined that further opportunity to develop and deliver education in the areas of pain assessment and management were a priority. We are now looking at ways that we can develop the possibility of offering further training and support in collaboration with APHN and the hospice executive.

The experiences, hospitality, and education that we received on our visit have impressed on us that palliative care is practiced by many with the same goal of client centred care.

Grace Buchanan, Meg Sands



Opioid Availability in India

This comment is informed by an article by Um E-Kulsoom Shariff entitled An Epidemic of Pain in India published in the New Yorker December 2013.

There is currently before the Indian Parliament a Bill of crucial significance to palliative care patients and the palliative care movement in India.

The Bill amends the Narcotic Drugs and Psychotropic Substances Act 1985 in order to simplify the complex maze of regulations, bureaucratic obstacles and potential criminal liability for non compliance which that Act put in place. The Bill will abolish the current regulatory framework for the use of morphine in favour of one standard process which every state will need to follow.

The purpose of the original Act had been to limit the use of opium and it's derivatives for fear of misuse and addiction however the side effect has been to render the medicinal and scientific use of morphine virtually impossible for the vast majority of Indians suffering pain. This is despite the fact that India produces and then exports almost all of the opium produced worldwide.

The current parliamentary session finishes on 20 December and is the last session before general elections due next year. This Bill is among many due to be debated so it may not even be reached let alone passed before 20 December. It is said that if the Bill is not passed in this session it may never be passed.

The failure to pass the Bill will mean that morphine will remain out of the reach of most Indians. If it is passed then not only will a vast number of people reap the benefit of affordable and effective pain relief but the palliative care movement in India will enter a new phase. If morphine is to become more easily available then palliative care itself can also become accessible to the millions who need it.

In the meantime the Bill to bring about these changes sits in a holding bay in the Parliament in Delhi.

Alan Hebb

Editor's note. There will be one last sitting of the current Indian parliament in February, 2014.

Asia Pacific Hospice Conference, Bangkok, Thailand Oct 11-13th 2013

In October I was fortunate to attend the APHC in Bangkok. I had not previously attended one of this organisation's conferences and did not know what to expect. To my delight it was one of the highlights of my academic year, not to mention the culinary and sensory joys that accompanied it.

I arrived to sultry Bangkok in the middle of the night which was uncharacteristically quiet, but full of bustling, noise and wonderful street cooking smells the next morning as I ventured out.

Arriving at the conference centre was an assault of colours with huge vases of orchids and other fresh flowers everywhere including around the booths and registration desks.

Highlights for me in the sessions were a clear, straightforward and inspiring call to consider innovative ways of building the evidence base for our discipline given by Dr David Casarett. He discussed methods (such as comparative effectiveness studies) by which we may interrogate our routinely collected data to answer questions in a rigorous and meaningful way that does not involve randomized controlled trials.

Dr Meera Agar gave a characteristically clear, comprehensive and well presented overview and update of delirium research and management.

Dr Kashiwagi gave a very moving plenary session whereby he described his experiences and observations in the aftermath of the Fukushima tragedies in Japan. And Dr David Brumley delivered a fine, thoughtful presentation using other sources of study and art, in particular, poetry to explore in depth the nature of suffering and how we may understand the light that may exist even in the darkest spaces.

But perhaps for me the greatest highlight was the warmth of the hospitality of the Bangkok hosts and the freshness and excitement that was palpable throughout the meeting. This is the environment in which the best learning and the most enduring professional partnerships happen.

Jenny Philip

Chris Drummond returns to Tripura in February 2014 with Wendy Salmon

Together with Valerie Hughes, these dedicated supporters have held several fundraising events over the past year, for mattresses and other equipment for this centre, as well as for their flights. We salute your efforts and wish you and your Hamrahi site well for this second visit.

Public litigation challenge in the Supreme Court, India

Hopefully this will reach a hearing in the New Delhi Supreme Court in early 2014, after years of preparation. Pallium India is petitioning for:

1. a palliative care policy by Central and State governments
2. simplified narcotics regulations
3. inclusion of palliative care in medical and nursing curriculum.

Hamrahi participant honored

On 12 October 2013, Wendy Salmon (APLI member) was awarded the Community Development Award as part of the South Australian Palliative Care Awards. Wendy is planning to visit Agartala Regional Cancer Centre Tripura (India) with Dr Chris Drummond in 2014. Congratulations Wendy.

Lien /APHN and APLI meet in Colombo, in December, 2013

Dr Suharsha Kanathigoda coordinated this event, in which the APHN/Lien team and APLI met up to explore ways in which the growing efforts to establish palliative care in Sri Lanka might be supported by international agencies. Discussions began with the advocacy meeting arranged by NCCP Director, Dr Neelamani Paranagama and Dr Suraj Perera. Several presenters from Sri Lanka presented the work to date or in preparation, in curriculum development in nursing and medical training, university courses, presentations from those who had participated on intensive training in India and and also from Dr Udayargami Ramadasa who had worked as palliative medicine registrar in Sydney with Assoc Prof Meera Agar. It was heartening to hear the commitment of Dr Laxmi Somatunga, MOH Director General of Health Services for establishing palliative care in Sri Lanka in a comprehensive and integrated way.

East Oncology Group
Estd. 2013

The IGIMS (Patna Bihar), established an institutional group, the East Oncology Group, for doctors and researchers to focus on improving cancer care, including pain and palliative care.

The EOG is supported by the Jeev Daya foundation, an American-based NGO, dedicated to improving palliative care for patients in India. The EOG states as an aim the building of networks across primary healthcare and tertiary hospital in order to deliver palliative care to patients in their communities. EOG also aims to foster conferences and education opportunities, establishing a related body, ONCOCON, which has held the first national haematology conference in Bihar in

September 2013.

Pallium India opens new IPU

After an interval of several months, spent searching for new premises, Pallium India has reopened its inpatient unit, at Arumana Hospital. Congratulations to all the staff for remaining steadfast in their search for suitable premises and achieving this long-desired goal. Thanks to the Pallium team and the assistance of Gilly Burn and students from Iowa, the unit was decorated and completed on time for the planned launch on 3rd January. A great way to bring in the New Year.

IGIMS, Patna, Bihar no longer a Hamrahi site

After 2 trips (2010, 20122) to IGIMS, Patna, Bihar, APLI and Pallium India took the decision to cease linking with IGIMS for the present time. Three staff members were trained in Pallium India 6-week intensive course. However on return to their institution, they were not supported to establish the palliative care service. The ongoing lack of availability of oral morphine also made the practice of palliative care and pain management very difficult in this major cancer centre. We hope that this link might be resumed in the future.

There is another centre to the north of Patna, Nazareth Hospital, which has been more successful in establishing palliative care services. At the present time, this in the only palliative care service, which is operating in this densely populous and impoverished northern state.

Building Bridges

– International Collaboration of Palliative Care

Thanal Charitable Organization sent a report to APLI entitled

"Building Bridges – International Collaboration of Palliative Care".

An excerpt from this shows the value of this collaboration to this newly established service.

"Thanal Charitable Organisation established palliative care in Lakshadweep few months back and now this NGO has extended its arms to a global level by a project named Hamrahi.

It is a joint venture of Australasian Palliative Link International and Pallium India Trust, a national NGO in India. The term Hamrahi means "fellow traveller" and was chosen to describe the shared journey of palliative care providers regardless of country. This can also describe our willingness to travel with those in pain and suffering and help them to lead a better life.

It is the first time in Lakshadweep that an international organization has come for good quality health care.

Thanal had a dream project by the theme of Building Bridges, and that dream has come true when the distinguished guests visited Kavaratti Island. Dr. Sophia Lam, Registrar of Palliative Care Unit, Monash Medical Centre, Victoria, Australia and Ms. Sarah Rose, Palliative Care Nurse Specialist, Melbourne City Mission, Australia visited the palliative care centre here in Kavaratti and shared their knowledge.

The Project Hamrahi is inaugurated by Shri.V.C.Pandey, IAS Secretary (Health) on 17.11.2013 at Paradise Hut. In his inaugural address he stressed on the importance of home based palliative care and intense modification of current health care system in Lakshadweep.

Shri.Achada Ahmed Haji (President- cum-Chief Counsellor, District Panchayath) spoke about the emotional pain of the isolated one and solace of those in pain when we give company to them. He also spoke about his concerns over social disintegration and the more nuclear family.

The function was presided by Mr. Moulana, Chairman & Director of Thanal Charitable Organization. During his elocution, he raised questions on the purpose of humans and reflected that the help and service of fellow travellers makes life happy and worthy. Smt.U.P.Umaiban (Chairperson, VDP) pointed out the need of more female nurses and volunteers in this field because most of the patients are ladies.

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Dr.Abu Laize, Deputy Project Manager of Pallium India gave felicitation on behalf of Pallium India and spoke to the audience for the distinguished guests of Australia. The Australian palliative care team also spoke and congratulated Thanal on their impressive work and the dedicated service of the palliative care team in Kavaratti. During their stay, they visited almost all the palliative care patients and made suggestions for future endeavours.

Other leaders, department heads and self help group were present at the function. Dr. Ali Azher, Palliative Care Doctor and Mr. Thabeebul Alam CN, Secretary of Thanal delivered the welcome speech and vote of thanks".

Lessons

Two decades ago, I passed out of medical school
Fresh as mint, cucumber cool.
I was always best in class,
Full of knowledge, no one could surpass
Medical textbooks were Bible to me,
ECG, ECHO, Angio were the diagnostic key.
Looking for pathology was the main issue,
To me, it was all disordered blood, bone and tissue.
Day in, day out like a robot,
Finding the correct diagnosis was all I sought.
Updating knowledge, what's latest and hot,
Delivering it to the patients was most vital, I thought.
Pills, injections, catheters and balloons
I believed were medical miracle and boon.

Two decades later, I now realise
In such a practice there is no prize,
I forgot, there was something more,
Left out in the medical curriculum core
To hold a hand and wipe a tear
A hand to support, a pat to cheer
Even the worst disease, on a deadly trail,
Where all the medical high-tech fail,
A little compassion can make us sail,
Through rough waters and sudden gale.
A child's smile and parent's thank
Is all the balance that I have in my bank
Looking back, I think I was a fool,
Mint fresh, cucumber cool.

Dr Tiny Nair is Head,
Dept of Cardiology,
PRS Hospital,
Thiruvananthapuram.

This poem was published in the Hindu paper on 22-12-13