THE APLI News

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Low Tech, High Touch - Palliative Care in India

Susan Poole
Deputy Director of Pharmacy
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In February this year I was invited to join Dr Odette Spruyt, Director of the Pain and Palliative Care Unit at Peter MacCallum Cancer Institute, to participate in a series of teaching sessions to new and experienced Palliative Care practitioners at various centres in Kerala, the most south-western state in India.

My over-riding impression of India is one of tremendous colour; not only as a visual impact, but also in character, resourcefulness and passion. The people we worked with are all immensely committed to the cause of Palliative Care, often forfeiting significant career opportunities to follow their heart-felt need to care for people in need.

After attending the Seventh International and National Conference of Indian Association of Palliative Care in Bangalore we travelled overnight by 'luxury coach' to Sulthan Bathery. Here we participated in the inauguration of Wayanad Consortium of Palliative Care. This event symbolised the spirit of many of the practitioners we met. The Consortium is the unique resource-sharing venture between three Palliative Care clinics; one run by a Catholic mission, one by a Hindu Mission, and the third by a government hospital. These three groups have been able to put aside their many differences and pool their resources for the benefit of their patients.

At the Calicut University hospital we ran several case-based teaching sessions for experienced palliative care physicians, most with an anaesthetics background. It was extremely rewarding to participate in the clinic sessions, where we were able to see a number of patients. I found it interesting to observe many differences in practice, but a holistic approach to patient care was certainly one of the primary principles.

We conducted introductory teaching sessions at the Indian Medical Association regional meetings in Northern Wayanard and Vazhakulam, where some colourful discussion was generated. Finally we took part in a very rewarding two-day seminar on Pain and Palliative Care at the Amala Cancer Hospital.

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Editor's note...

Welcome to the first edition of APLI Newsletter for 2000. We have a bright and smart new format, thanks to the work of Liz Bearzatto and the ongoing sponsorship of Mundipharma. It is great to be able to add some colour and style to the newsletter.

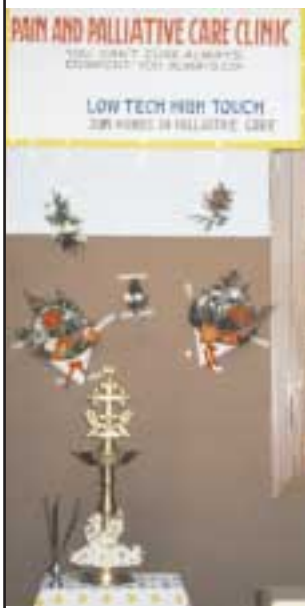
This edition contains two articles. The first is from Ms Susan Poole, Deputy Director of Pharmacy at Peter MacCallum Cancer Institute. Susan recently went to India to participate in a week of teaching and writes of her impressions of the country and teaching experiences. The second article is from Ms Susan Bray, RN, Central Sydney Palliative Care Service. She attended the recent conference in Israel, Palliative Care: Multicultural aspects. The article includes one of the photos from the poster which she displayed at the conference.

Thanks to both contributors for their insights. Contributions, comments and feedback are always welcome for the newsletter.

Our APLI website **(www.petermac.unimelb.edu.au/apli)** is in need of an update and we are on the lookout for a willing and talented volunteer!

Also a special reminder that 15th May through to 19th May is Volunteer's Week, a chance to remember the essential contribution of volunteers to the Palliative Care mosaic. ***The Editor***

Inside this Issue



Pain and Palliative Care Clinic in Sulthan Bathery, Kerala, India.

APLI News acknowledges the support of MUNDIPHARMA

Overall, I found the experience extremely rewarding, I was continually amazed at the resourcefulness and ingenuity of heath-care workers who frequently face lack of funds and access to medications. Everyone we met was extremely friendly and showed great hospitality whenever the chance arose. From my perspective as a pharmacist, it has provided me with many opportunities for collaboration and support. This first trip to India will remain a treasured memory, which I hope I may repeat in the future.

Report on Palliative Care Conference in Israel

Susan Bray

I had the privilege and pleasure of attending 'Palliative Care 2000; Palliative Care in Difference Cultures', hosted by Israel, in collaboration with the European Association of Palliative Care and held in Jerusalem from March 19-23, 2000.

The final day of the conference was on Wednesday, 23rd March, and on Thursday 24th, was the commencement of the historical visit of Pope John Paul II to Israel, bringing repentance and reconciliation.

THOMAS O'DWYER, a journalist writing for Ha'aretz, one of the daily English newspapers in Israel wrote, "It was expected that something surely must go wrong when Pope John Paul II would step amid the narrow stone lanes and some of the narrow closed minds that house the three great monotheistic faiths in bad-tempered Jerusalem, but John Paul's diplomatic agility and personal will triumphed over would be troubled waters. The images that will be remembered and that will endure are those of an old and suffering holy man given superhuman endurances by the power of his faith".

ARI SAVIT wrote in the same newspaper, "Suddenly, banal politics ceased. The routine conflict of interest froze in their tracts, for compassion was here on a royal visit and stretched over this land. The nine million displaced persons and children of displaced persons inhabiting this promised, neurotic, violent land, suddenly had the opportunity to express spiritual cleansing, a symbolic catharsis, that only a Catholic knows how to direct and suddenly despite it all, we will succeed in talking to one another, Christians and Jews, Jews and Palestinians, remembering what needs to be remembered and forgetting what needs to be forgotten".

I thought these impressions were worthy of mention when talking about palliative care in different cultures. The Pope's visit to Israel illustrated his acceptance and compassion, his humanity and fortitude and the desire to bridge barriers, leading towards greater understanding and reconciliation between different cultures, races and religions.

Returning to the conference, there were many interesting speakers and thoughts to absorb, from many countries, some occurring at the same time, consequently I missed talks I would have liked to have heard. However, I will summarise those which created the strongest impression on me.

"his humanity and fortitude and the desire to bridge barriers...."

Patient – from poster presented by Susan Bray to PC2000 Conference.

RABBI YAAKOV WEINER, the Dean of the Jerusalem Centre for Research, Halacha & Medicine, Israel, spoke of death as being the 'ultimate atonement'. Suicide is looked on very severely in orthodox Judaism. Any life-threatening situation is given priority over all the commandments of the Torah (excluding murder, idol worship and adultery) and that all is done in order to save a life. In such a case, the laws of Sabbath & Yom Kippur are suspended in order to alleviate pain, fear or other psychological agitation. The importance of assuring the patient's comfort and good spirits are stressed, therefore encouragement and hope remains at death (rather than truth or reality).

PROFESSOR SHARON KAUFMAN, an anthropologist from the University of California, spoke of the cultural difference in the dying process, using case studies in America, Haiti and Italy. Robert, in Boston, was suffering with an HIV Aids infection and treated in hospital against his wishes. She spoke of the notion of 'death with dignity' as being a cultural response, both to the use of high technology hospital medicine and the institutional press towards curative

and restorative therapies, regardless of the patient's biography and nearness to the end of life. She calls it the 'autonomy-control' narrative, dominent in the USA., characterised by self-determination, individual choice and knowledge in the context of medical technology. 'Control' is sovereign, and life is largely controllable.

Whereas, in Italy there exists a 'social-embeddedness' - in the beginning, God - the family. Personhood is relational, 'being' is part of something larger. 'Art' not 'science' is the metaphor for this culture and knowing 'the truth' less relevant; there is another reality to make people feel better. In Haiti, a dying woman was cared for simply at home by her god-daughter (? with symptoms well controlled) . She sees the American model as harsh and lonely - instead of resting, to be active and rational towards one's end.

DR SEBASTIANO MERCANDANTE from Palermo, Italy, spoke in relation to measurement of outcomes of symptom control and parameters of quality of life. He says in oncology, quality of life is now recognised as an end point of secondary importance only to survival, whereas in palliative care, quality of life is prominent. He adds quality of life is a multi dimensional concept and very subjective in nature and doesn't fit into a traditional medical model of assessment. He states it is a challenge for future research. He related a nice anecdote about asking his old uncle, who is in his 80's what does quality of life mean to him nowadays? After thinking for a moment, his uncle replied, "When I wake up in the morning I would like a beautiful, young woman to be beside me, and another young woman to spend weekends with in the countryside and I would like to own an island, where a beautiful woman waits for me". Dr. Mercandante also spoke of using parental nutrition in some instances, saying there is no disease that benefits from severe wasting. He suggested that quality of life is gained by giving a metabolic and psychological advantage, so why not use it, particularly if people want it?

DAVID BARNARD from the Centre for Bioethics and Health Law, University of Pittsburgh, USA, spoke about 'Palliative Care as a Bridge between different cultures'. He states palliative care workers have typically adopted one of these orientations towards religious and cultural differences.

'UNIVERSALISM' - death and loss are fundamentally the same for everyone.

CULTURALISM - practice regarding death and loss are very real and can be explained and predicted with reference to the cultural group, and thirdly, INDIVIDULISM - tailored to the needs and preferences of the individual.

He says each of these has shortcomings, e.g. UNIVERSALISM is a cultural ideology imposed on individuals. The pitfalls of CULTURALISM are stereotyping, reductionism, romantic idealisation and ignoring structural and power dynamics of health care.
With INDIVIDULISM it can blind us to social and political forces; it ignores our embeddedness (no man is an island) and perpetuates a tyranny of autonomy which is also a social contravention and can be seen as abandonment. He sees a fourth orientation, taken from elements of the other three, can help palliative care build strong bridges between different cultures, using the qualities of openness, risk taking and empathy, within a structure where there is access and approachability of palliative care services.

DR SIMON WEIN from the Department of Palliative Care and Medical Oncology, SHAARE ZEDEK Medical Centre, Jerusalem, spoke of depression, saying it is under estimated and under treated in palliative care. He breaks down depression into emotional (sadness); cognitive component (pessimism) and hopelessness (increased suicide). He says with sadness and hopelessness there is no future, no escape. He spoke of the association of depression to death, pre-occupation with death, psychological pain, loss of will, to much pain - desire to escape. His message was the relationship of 'hope' to depression, i.e., hopefulness counters depression.

Finally, from JACOB SCHWEIZER, a psychologist from Ramat Gan Hospice, Israel, who has developed a technique called 'RESONANCE' to help existential suffering. He quotes HEIDEGGER, 'the essence of human existence, because of its transcendental nature is worry about the future'. He states real existence is in this moment. If a patient is in this moment, there is less fear. Separateness leads to anxiety; hope increases when separateness disappears. He concentrates patients in the moment using relaxation, meditation, hypnosis
* inner experience. The technique of 'RESONANCE' consists of creating an intimate environment, in which the therapist can absorb 'negative' feelings, then leads himself into a specific state of mind, e.g., to an anxious patient (or relatives) the therapist can resonate 'calmness' - this can merge into the patient's state of being: merging and unification with the unwell can be felt sometimes.

The committee in Israel organised enjoyable 'get-togethers'. The 'night of nights' was celebrating the Jewish festial of 'Purim", which happened to fall on the Tuesday night. Apart from a wonderful show and delicious food, many of us danced all evening to music which spurned all cultures and spoke the same language.

Shalom

APLI Website

Our website needs urgent updating. Anyone interested in volunteering, please contact Dr. Odette Spruyt - email: odettespruyt@peter-mac.unimelb.edu.au

Announcement from Newsletter of IAHPC

Executive Director's Message,

Bette Michael, EdD (in March edition of IAHPC newsletter announced the formation of the INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE

We are pleased to announce that we are now a new non-profit charitable organization, The International Association for Hospice and Palliative Care (IAHPC), incorporated in the State of Michigan in late 1999. An application has been filed to establish this organization as a 501 (c)(3), 509(a)(2) charitable organization.

Most of the Board of Directors has served on the Board of IHIC, a Virginia Corporation, also a non-profit charitable organization. Under that organization, travelling fellowships were created, and many working relationships forged. The intents and purposes of IHIC are, in many ways, mirrored in IAHPC. Despite the similarities of purpose, however, IAHPC is not a legal successor to IHIC, nor are the two organizations linked in any way.

The IHIC organization is being dissolved. Information about Travelling Fellowships and other IAHPC programs, and additional promotional materials, will be made available in the near future.

We welcome our members and friends to IAHPC!

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

Montreal conference

13th International Congress on Care of the Terminally Ill, Montreal, Quebec

TWO IAHPC WORKSHOPS

1. Tuesday, 26th September, 2000
   1400 - 1515
   Speaker: Wendy Jones
2. Wednesday, 27th September, 2000
   1400 - 1515
   Speakers: Susan Volker, Marie Coglan and Dr. Derek Doyle

Countries of focus will include Russia, Columbia, Saudi Arabia, Mongolia and India.

Dr. Doyle's lecture is titled ***'Essence of Palliative Care.'***

APLI Supports

Conference News

The Hospice Foundation of Taiwain is hosting **Asia Pacific Hospice Conference** 2001 in Taipai, Taiwan. There has been a change in dates to 2nd - 5th May 2001.

The conference theme is 'Global Challenges - Local and Regional Adaptations'

The 8th Indian Association of Palliative Care Conference is in Bhopal, M.P. India, 2nd - 4th February 2001

Membership

APLI invites new members.
$40 new member
$20 annual renewal

Fifth World Conference of Psycho-Oncology

3 – 7 September, 2000

Melbourne Convention Centre

Contact:
The Conference Organisers
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