

International Association for Hospice and Palliative Care (IAHPC)

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July 2011

RE: The July edition of the IAHPC Newsletter

Dear Members and Colleagues:

The July issue of our newsletter is now on our website at <http://www.hospicecare.com/news/11/07/>.
A very abbreviated edition may be found below.

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Warm regards,

Roberto Wenk, MD, Chair
William Farr, PhD, MD, Vice-Chair and Editor

Message from the Chair and Executive Director

Dear readers:

This month, we want to highlight several advocacy initiatives to improve access to pain treatment and palliative care.

Millions of people experience severe pain every year and don't have access to adequate treatment. Many suffer other physical and emotional symptoms which are treatable and in many cases preventable. There are inexpensive treatments that can relieve most pain and other symptoms that can dramatically improve the quality of life of patients and their caregivers.

This situation is a result of a lack of educational experiences for health professionals in the assessment and treatment of pain and other symptoms, unduly restrictive laws and regulations which limit access to opioids for legitimate medical use, and a lack of recognition by policy makers and legislators about the dire needs of patients with life limiting conditions.

The campaigns and the initiatives that several organizations have adopted and implemented throughout the world during the last 6 months all point clearly to this suffering and the need to take the necessary steps to alleviate this global problem. They are:

1) British Medical Association (BMA) proposal to the World Medical Association: The BMA has submitted a proposal to the World Medical Association to adopt a resolution on the Access to Adequate Pain Treatment. To read the BMA resolution click on http://www.hospicecare.com/resources/pdf-docs/pain-relief-proposed-resolution_bma.pdf. How can you help? This proposal will be presented during the next WMA assembly in Montevideo, Uruguay, October 12-15, 2011. We need national medical associations from around the world to support and endorse this proposal so that it gets approved during the WMA assembly. You can help by contacting your Medical Associations, sending them the draft proposed by the BMA and asking them to send supportive emails to the International Federation of Health and Human Rights Organizations (IFHHRO) at ifhhro.statements@gmail.com. Ask them to vote in favor of the resolution when it is presented in the WMA assembly. This is a unique opportunity to bring global support for access to pain treatment. We need your help and support!

2) Treat the Pain: Treat the Pain is a campaign administered by the Union for International Cancer Control (UICC) to advocate for high-quality pain treatment for all those who need it throughout the world, and to connect those with meaningful actions who would like to join the fight. The campaign will use the resources and voices of its members to promote and advocate for universal access to adequate pain relief. The campaign includes the release of *LIFE Before Death*, a series of videos filmed in 11 countries across North America, Europe, Asia, and Africa. To read more about this campaign, watch the videos, and learn how you can become involved, click on <http://www.treatthepain.com/>

3) Palliative Care as a Human Right: Human Rights Watch (HRW) co-sponsored a side event on June 6th with the permanent mission of Uruguay and Brazil during the 17 th Session of the Human Rights Council in Geneva. The key note speaker of this side event was Professor Tabaré Vazquez, past president of Uruguay and current head of the radiotherapy service in the department of oncology at Uruguay's National Institute of Oncology. In addition, there was a panel moderated by Mr. Diederik Lohman, senior researcher at the Health and Human Rights Division in HRW. On the panel were three board members of IAHP: Dr Faith Mwangi-Powell, representing the African Association for Palliative Care, Dr M.R. Rajagopal from Pallium India and Ms. Liliana De Lima, representing the IAHP. During this event, several issues were discussed including barriers to the access of pain treatment, the question of how palliative care fits within the HR conventions, what are the obligations of countries, and a discussion on how countries and permanent missions may engage with governments to improve access to care at the country level. HRW will continue working to see if there is a possibility of:

- a Human Rights Council resolution specifically on palliative care;
- ways to ensure that recommendations are made regarding palliative care as part of the Universal Period Review process; and
- ensuring the place of palliative care in discussions about the rights of older persons.

The photo below was taken during the panel session – from left to right are: Professor Tabaré Vazquez, Dr. Faith Mwangi-Powell, Mr. Diederik Lohman, LDL and Dr. M.R. Rajagopal.



(photo courtesy of Dr. MR Rajagopal)

IAHPC is proud to be part of this movement and we will continue to help as much as possible to achieve these objectives in alliance with all of those around the world who want to eliminate needless suffering. We hope that these campaigns will also inspire all of you to take action and become a part of this much needed and exciting movement.

Until next month,

Roberto Wenk, MD
Chair, Board of Directors

Liliana De Lima, MHA
Executive Director



MAKING GLOBAL ACCESS TO PAIN RELIEF PERSONAL!

by IAHPC Board member James F. Cleary, MD, FRCAP, FACHPM, -- from his blog*



April 8, 2011: It is 4:30 am here in Hong Kong. I am awake. Jet Lag.

I am attending the 3rd Asian Oncology Summit hosted by Lancet Oncology and Elsevier.

....Up to 70 million people/year may be experiencing untreated severe pain at the end of life in Asia alone....Cancer is and will continue to be a growing problem in Asia along with the other non communicable diseases.... Dr Judith Mackay, a Hong Kong physician,... reminded me that last year during a question time, I had asked, "How many of you, if diagnosed with an advanced cancer, would want access to opioids for the treatment of cancer pain?" I raised my hand from the podium to show I was looking for a response. 3000 hands were raised! Okay I didn't count, but I could see a sea of hands across the cavernous hall....

I first asked this question while working with Dr Daniela Mosiou and her colleagues in Romania to address the barriers to opioid availability in their country... There too [*editor's words added*]...All hands went up progressively around the circle until even the drug police to my immediate right had their hands raised. I then ask, "Why are we denying the people of Romania access to opioids for pain relief?".....

Romanians are no longer denied access to opioids for pain relief. That is not to say that everyone who needs them gets them. This is a long process,...morphine is a 200 year old drug, the use of which still seems novel, despite the 1961 UN Single Convention on Narcotic drugs...."The medical use of narcotic drugs continues to be indispensable for the relief of pain and suffering...adequate provision must be made to ensure the availability of narcotic drugs for such purposes." (Preamble, page 13).

The Pain and Policy Studies Group (PPSG) has been about ensuring the availability of narcotic drugs for the relief of pain and suffering. We do not make decisions on what is an appropriate medical purpose....Dave Joranson took this "concept of balance" from PPSG to the WHO and the second edition has just been released by the WHO, under the leadership of Willem Scholten, and endorsed by the International Narcotic Control Board:

http://www.who.int/medicines/areas/quality_safety/guide_nocp_sanend/en/index.html

We must prevent abuse and diversion while *ensuring* availability for medical purposes.... Should opioid use only be limited to those with advanced cancer?....Yes... this is personal for me, too. Like you, I want ready access to opioids if I am faced with an advanced cancer diagnosis. I want this for me, my wife and my children and I want it for my mother, even though she doesn't have cancer.

And I am sure it is personal for the millions of people around the world who are suffering from pain and have no access to pain relief.

The entire unedited story related in Dr. Cleary's Blog may be found at

<http://painpolicy.wordpress.com/>

The above piece was previously published in the aforementioned site and a condensed and edited version is reprinted at http://www.hospicecare.com/news/11/07/pain_relief.html with permission.

Dr. Cleary is a member of the IAHP board and his complete bibliography may be found at

<http://www.painpolicy.wisc.edu/PDFs/Bio/ClearyBio.pdf>

New WHO publication available to help improve access to treatment

Ensuring Balance in National Policies on Controlled Substances

Guidance for Availability and Accessibility for Controlled Medicines

This book from the World Health Organization provides guidance on policies and legislation with regards to availability, accessibility, affordability and control of medicines made from substances regulated under the international drug control conventions, herein referred to as “controlled medicines”....

This book elaborates on the background and then provides 21 guidelines on various topics: content of drug control legislation and policy; authorities and their role in the system; policy planning for availability and accessibility; healthcare professionals; estimates and statistics; procurement; and nationally listed drugs. Each guideline has an elucidation and a description of the legal context. The Country Assessment Checklist enables the user to determine which guidelines still need to be worked on. A CD-ROM provides additional information.

Target audience: policy-makers, regulators (in government, administrative departments, national competent authorities) and politicians; academia and civil society; healthcare professionals and their organizations; individuals (including patients and their families) and organizations whose area of work or interest is drug control or public health.

Book and reference list **freely downloadable** online in 14 languages at http://www.who.int/medicines/areas/quality_safety/guide_nocp_sanend/en/index.html and the Repository of the WHO Library: <http://dosei.who.int/uhtbin/webcat>

Available in hardcopy in English and French:

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[F]: 78 pages, ISBN 978 92 4 256417 4, Order no. 21500807

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Email: bookorders@who.int

Web site: <http://www.who.int/bookorders>

Human Rights Watch Reports on “Uncontrolled Pain” in Ukraine

Tens of thousands of patients with advanced cancer in Ukraine unnecessarily suffer from severe pain every year because they cannot get effective, safe, and inexpensive pain medications, Human Rights Watch said in a recent report. The 93-page report, "[Uncontrolled Pain: Ukraine's Obligation to Ensure Evidence-Based Palliative Care](#)," describes Ukrainian government policies that make it impossible for cancer patients living in rural areas to get essential pain medications....

Take action : Click here <http://www.hrw.org/en/features/ukraine-pain-free> and write a letter to Ukraine's minister of health urging him to introduce oral morphine.

The entire article may be found at http://www.hospicecare.com/news/11/07/human_rights.html

Diederik Lohman
Senior Researcher
Health and Human Rights Division

An IAHPIC Traveling Scholar's Report – Turkey



I want to thank the International Association for Hospice & Palliative Care for providing financial support to participate in the 12th Congress of the European Association for Palliative care in Lisbon (18-21 May 2011).....

This congress was useful in that it will help me to provide optimal care for my terminally ill patients....I saw how far behind my country is in palliative care and opioid use. What do I do?

...I am not content here in Turkey because of the many difficulties-- everything develops slowly here. It is impossible to do it alone and therefore support and expertise from abroad could help Turkey move in the right direction sooner rather than later.

Read the entire scholar's report at http://www.hospicecare.com/news/11/07/travel_scholar.html

Dr. Serpil OZSEZGIN OCEK
Anesthesiology and Reanimation
Izmir-TURKEY

Also from Dr. Serpil Osezgin Ocek -- A regional report -- Turkey

I am an Anesthesiologist and Reanimation specialist living and working in Turkey. More than 74 million people live in Turkey but unfortunately, there is no palliative care specialisation in Turkey.

Narcotics are often available to meet the needs of dying patients with chronic pain. Many private pharmacies however shun the bureaucracy and the potential liability that goes with dispensing "green" prescriptions (addictive or abusable drugs) and "red" prescriptions (narcotics). Our hospitals and their staffs are not organised or trained to provide palliative care....

... we lack a range of strong opioids because only slow release morphine, transdermal fentanyl and tramadol are available. The fear of psychological or physical addiction to strong opioids is prevalent....Therefore, the use of opioids in Turkey is limited....

After becoming aware of this situation, I opened a private Pain-free Life Centre in 2000 in order to deal with the management of pain in end-stage cancer patients....I was able to provide intensive care in their homes by being available at all times, 24/7.

Dealing with death openly is considered taboo in Turkey....Commonly observed thanatophobic attitudes of healthcare providers, especially doctors, facilitate isolating the patients in a condition of despair and exhaustion....I have noted considerable changes in my own thinking about death during the ten years since starting the Center for Painless Living. My challenge is to find effective ways to share my experiences and knowledge with others in order to improve end of life care wherever I can.

Dr.Serpil OZSEZGIN OCEK

To read the entire report please go to http://www.hospicecare.com/news/11/07/regional_report.html

Article of the Month

Assessment of palliative care cancer patients' most important concerns

Baile WF, Palmer JL, Bruera E, Parker PA
Supportive Care Cancer 2011; 19: 475-481

Medical problems are only a part of the concerns of cancer patients that cause suffering. It is well known that the treatment of TOTAL PAIN is a major objective of palliative care but in order to personalize treatment it is important to assess on a regular basis all the issues confronting patients.

The aims of this study were:

- to assess the concerns of patients who attended a palliative care clinic and determine their association to the level of distress provoked,
- to examine the ratings of physicians regarding patient concerns, and
- to assess the concordance between patient and physician ratings....

The entire article may be found at <http://www.hospicecare.com/news/11/07/aom.html>

Palliative Care Book of the Month

END OF LIFE. Nursing Solutions for Death with Dignity.

Keegan and Drick

A vision for more holistic care around the time of death. Recommended.

To read the review go to <http://www.hospicecare.com/news/11/07/reviews.html>

Another Review

GOVERNING DEATH AND LOSS. Empowerment, involvement, and participation.

Steve Conway (ed.)

What people are thinking and doing, around the world, to help our communities cope better with death and loss.

To read the review go to <http://www.hospicecare.com/news/11/07/reviews.html#1>

Dr. Roger Woodruff (Australia).
(June 2011)

Dr. Woodruff is a Lifetime member of the IAHPC board and his bio may be found at http://www.hospicecare.com/Bio/r_woodruff.htm

Announcement

Changing the behavior of oncologists in Jordan. The authors state, “We conclude that “Western style” experiential training that contradicts very traditional approaches to doctor–patient communication in a traditional Arab country is effective.” Read the letter to the editor in the following reference.

Amineh A.S. Al-Tamim and Mohammad Bushnaq: Communication and Skills Workshops for Oncologists in Jordan. *Journal of Palliative Medicine* 2011; Vol 14 (4), 387

Membership numbers

We wish to thank all of the people and institutions for their support during the past month.

A complete list is provided at <http://www.hospicecare.com/news/11/07/support.html>

Webmaster's Corner

Website Of The Month - Canadian Hospice Palliative Care Association

CHPCA is the national voice for Hospice Palliative Care in Canada. Advancing and advocating for quality end-of-life/hospice palliative care in Canada, its work includes public policy, public education and awareness.

<http://www.chpca.net/>

Until next month!

Anne Laidlaw
IAHPC Webmaster

Best Wishes,
Roberto Wenk, MD, Chair
William Farr, PhD, MD, Vice-Chair and Editor

William Farr, PhD, MD - Editor
Liliana De Lima, MHA - Coordinator
Anne Laidlaw - Layout and Distribution